Functional outcome after spinal cord injury

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Functional Outcome after Spinal Cord Injury: Activities and Participation

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Functional Outcome after Spinal Cord Injury: Activities and Participation

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Voorwoord

Dit onderzoek naar het functioneren met een dwarslaesie startte tien jaar geleden tijdens mijn opleiding tot revalidatiearts. Op 17 februari 1994 vond op de oude afdeling Revalidatie van het AZG in het Transitorium de eerste onderzoeksvergadering plaats met een drietal begeleiders, later begeleidingscommissie geheten. Gaandeweg is het project uitgegroeid tot een serieus promotieonderzoek. Er zijn veel mensen die mij bij het schrijven van dit proefschrift hebben gesteund, waarvoor ik hen hartelijk wil bedanken. Enkelen van hen wil ik in het bijzonder noemen.

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Marleen Schönherr
Thesinge, oktober 2003

Contents

Chapter 1

Introduction

Patients with spinal cord injuries (SCI) are confronted with motor and sensory deficits and dysfunction of bladder and bowel, leading to a fundamental change of life. Until the Second World War the majority of patients with SCI died due to complications, often leading to fatal infections. At first the research of outcomes after a SCI was focused on survival rates and medical consequences in the acute phase. In the last decades there has been a shift of interest to the impact of the SCI, illustrated by the physical and psychosocial consequences for the patient. According to the World Health Organisation's International Classification of Functioning, Disability and Health (ICF)[1] the functional outcome can be described in three dimensions, namely functions and anatomical structures, activities and participation.

Knowledge of the functional outcome is indispensable to provide accurate prognostic information for the patient and family. Moreover, it is essential to improve acute medical treatment and rehabilitation, to evaluate the quality of care and to set out health-care policies for SCI disabled. Because of the extensive medical, emotional and social consequences of SCI, multidisciplinary management is essential. All over the world rehabilitation programmes have been developed in order to enhance the functional outcome after a SCI. Important goals of rehabilitation are to maximise the independence in daily activities and to provide optimal reintegration in society.

The aim of this thesis was to increase our knowledge of the functional outcome after a SCI on the level of activities and participation. The study provides insight in several aspects of the process of rehabilitation, from admission to the rehabilitation centre until several years after reintegration, and explores the role of the individual patient and professionals in the rehabilitation and reintegration process. Recommendations regarding the whole continuum of care will be given in order to improve the rehabilitation programmes for patients with spinal cord lesions based on realistic goals.

Research on outcome after SCI

Since Guttman started to focus attention on the rehabilitation aspects of patients with SCI after World War II[2], many studies addressed the outcomes following SCI in different regions all over the world. Epidemiological studies from several countries presented the incidence of SCI. A reliable assessment of the incidence in The Netherlands was not yet available. Globally the incidence varies from 9 to 53 spinal cord lesions per million inhabitants per year. In Europe the incidence is generally low (9 to 16 / million/ year)[3-6]. Assessments in 1990 estimated a rate of 30 to 32 new traumatic SCI per million in the USA and 39.4 per million in Japan[7,8]. Apart from sociological and demographic differences the variance is explained by the definition of SCI used in different studies. Most studies concentrate on patients with traumatic SCI. In European studies 25 to 39% of the spinal cord lesions was non-traumatic and characteristics of these patients differ from those with traumatic lesions[3-5]. Peaks are found in the younger age groups for traumatic injuries and in the older age groups for non-traumatic lesions. The majority of patients with traumatic injuries are male, whereas non-traumatic lesions are more equally divided over both sexes.

Activities

Impairments such as motor and sensory loss and impairments of bladder, bowel and sexual function are the most important physical consequences of a SCI, leading to extensive disabilities in activities of daily life. Health problems that often develop secondary to the SCI are pain, spasms, pressure sores, urinary problems, bowel problems, respiratory failure, oedema and excessive sweating[9]. In several studies by Waters *et al.* the motor and sensory recovery following traumatic SCI was quantified, using the initial level of injury [10-12]. Most of the neurological recovery occurs within the first six months after injury[10].

The degree of functional improvement, which is more relevant in predicting rehabilitation outcome, depends on the level and extent of lesion. Various theoretical models have been developed and studied to predict potential physical abilities based on spared motor and sensory functions[1,16]. Many articles focus on self-care of patients with tetraplegia[1-19]. C6 and C7 are critical levels for achieving independence in daily activities. Most authors agree that patients with paraplegia can achieve independence in self-care skills[14,19]. Ambulation is the subject of several studies with a diversity of results[20-24]. Nene *et al.* presented a review of reports concerning locomotion[23]. There is considerable difference in opinion regarding a patient's ability to walk and the use of orthoses. Most authors generally accept that patients with complete lesions above T10 are incapable of functional locomotion. The outcome of bladder and bowel care after SCI is comparatively unknown. Advances in urological pharmacology and sacral root stimulators have led to better urological outcome.

The functional performance of those patients also depends on other factors, such as age, co-morbidity, health problems, motivation and coping[15,16]. Studies that actually evaluate the functional prognosis as predicted by professionals are rare[12] and the expectations of the individual patient regarding his functional outcome were never examined.

Participation and reintegration in work

Most people with SCI are able to live in their community after the rehabilitation process. A significant number of them achieves independence in daily activities. Reintegration in work, leisure activities and sports is considered to be a subsequent important goal of rehabilitation. Active involvement in activities and roles is strongly related to health and well-being[25] and a high level of social activities leads to a better quality of life[26,27]. According to the ICF participation in society includes reintegration in work and school, but also significant involvement in housekeeping and community organisations[1].

In literature many reports were published on the quantitative outcomes of employment after the SCI, mainly expressed as work rates. The variation in study groups makes it difficult to compare the results of different studies. American studies in the eighties showed poor rates up to a maximum of 25% of persons being employed after SCI[14,28-30]. In more recent American, Australian and European studies the percentages of persons gainfully working improved and ranged from 31 to 48%[27,31-33]. In a Dutch multi-centre study Tomassen *et al*. reported that 37% of pre-injury workers were gainfully employed after SCI[34].

Returning to work is a complex process that results from an interaction of impairment and personal and environmental factors [25]. Predictors of successful job reintegration are subject of a lot of research on vocational outcome of persons with SCI[14,27,31-38]. Several studies focused on demographic and injury-related factors, such as age, type of lesion, Barthel Index and time elapsed since injury. Work-related factors were studied, including educational level, pre-injury employment status, vocational re-training, social security system, financial disincentives (losing benefits when becoming gainfully employed) and work place discrimination. Also environmental factors such as transportation and architectural barriers apparently played a role. Only few studies focused on the role of subjective indicators such as work interests and values, educational and vocational plans and societal attitudes[28,32]. Expectations of the individual patient regarding work, were scarcely studied in relation to vocational outcome.

For those persons who were not able to reintegrate in work, participation in non-vocational activities must also be considered as a successful rehabilitation outcome. Only few studies have described the outcomes of participation other than traditional employment[25,27,35,37]. The assessment of these non-vocational outcomes is more difficult, since those activities are

more complex to quantify in everyday life. A major shift in time use occurred from time spent on social activities to personal care activities.

Quality of life

Attaining an acceptable quality of life can be seen as the ultimate goal of rehabilitation. Satisfaction with the quality of life after a SCI depends on the way a patient learns to adapt to fundamental changes in his life. Various objective and subjective determinants of quality of life after a SCI were studied in literature. More subjective approaches focus on the person's satisfaction with those aspects of his life situation thought to be affected by the particular disability under study[26,39]. Some authors found that life satisfaction among persons with SCI is relatively good and in a few studies even better than their peers[40,41]. Other findings indicate that people with SCI who live in the community report a lower level of satisfaction with life[42]. Post *et al.* also found a lower general life satisfaction than in the Dutch population group, but some differences disappeared after adjustment for age and marital status[43]. Satisfaction with the vocational situation is usually low[9,42]. For those persons who returned to work after the SCI this can be explained by unrewarding, poor-quality jobs and insufficient income[26]. Information about the satisfaction with non-vocational participation in other activities is scarce[25,27].

Dutch research on outcome after SCI and outcome measures

In the last decades several interesting studies have been done in The Netherlands. Their results were of great importance to the rehabilitation medicine in The Netherlands in general, and the rehabilitation of people with SCI in particular. Van Asbeck performed a descriptive study regarding the functional outcome of persons with paraplegia in the Netherlands in his thesis of 1987[44]. De Witte analysed the outcomes of patients with SCI and other diagnoses after the rehabilitation centre[45]. Van Bennekom and Jelles presented the ICIDH as a framework for assessment in rehabilitation medicine in their dissertation of 1995[46].

In Post's thesis of 1997 a large-scale nation-wide study was performed regarding the health status and life satisfaction of people with SCI, including non-traumatic lesions[47]. It revealed various relationships between rehabilitation outcomes of different dimensions. He developed a conceptual framework for rehabilitation outcomes, which is an extension of the International Classification of Impairments, Disabilities and Handicap (ICIDH)[48]. In this model he added a subjective axis linked to the original objective outcome levels. "Somatic sensation, perceived health and life satisfaction" were indicated as subjective counterparts of respectively "impairment, disability and handicap". Besides, the concept of happiness was given a separate place in the framework.

In the meantime the ICIDH changed into a concept of "functions and anatomical structures, activities and participation", which means a positive

approach of rehabilitation outcomes (ICIDH-2). Personal and environmental factors recently have been incorporated in the model in 2001, leading to the renewed International Classification of Functioning, Disability and Health (ICF)[1].

Research on the process of rehabilitation

Following the definitions of the World Health Organisation of 1980 the philosophy of rehabilitation is to reduce disabilities and handicaps resulting from impairments caused by trauma or disease[48]. Wade described the core features of rehabilitation as follows: co-ordinated, multidisciplinary teamwork, by a team interested in disability, who actively involves the patient and family in the process, which is set in an explicitly recognised framework encompassing all aspects of illness[49]. Several studies were found in which aspects of the process of rehabilitation after SCI were explored.

Research on the process of interdisciplinary rehabilitation treatment following SCI is limited. In a framework for considering rehabilitation interventions Wade suggested evaluation of treatment on the levels of the ICIDH[50]. Rehabilitation interventions on the level of activities intend to alter the behaviour of the patient and family by teaching adequate skills and strategies, and alter the physical environment by providing appropriate equipment, adaptations and trained caregivers. Interventions at the level of participation ideally maximise the behavioural repertoire of the patient and provide suitable opportunities for social interaction, like educational and employment services. Participation outcomes are largely influenced by factors outside the influence of most health-care systems. Well-being is reduced if there is a discrepancy between a patient's behaviour and social-role functioning and too high expectations. Pain and anxiety are also important factors influencing well-being. Rehabilitation interventions on the level of well-being should focus on reduction of high expectations and treatment of distress.

The process of goal planning has received considerable attention in studies regarding interdisciplinary rehabilitation treatment[51]. The role of the individual patient in the process of rehabilitation seems very important. Fuhrer *et al.* mentioned that the subjective experiences of those involved are usually not represented in the outcome measures and generally neglected[42]. It is assumed that motivation and expectations of the patient regarding reintegration in society will affect the outcome to a great extent. In his editorial on evidence relating to goal planning Wade stated that goals are central to the process of rehabilitation[51]. Rehabilitation involves altering the behaviour of people and this can only be achieved if the patient wishes to attain a goal in agreement with the rehabilitation team. There was no evidence on the most appropriate method to undertake goal planning and this should be a challenge for further investigation on the impact of goals and expectations.

In the last decade the evaluation of the quality of health care has become an important topic. Health-care providers are stimulated to assess their performances in order to compare the health services regarding quality and efficiency. Various indicators of performance are selected that reflect the quality of care. It is essential that also in rehabilitation medicine attention is given to the settlement of adequate and validated quality indicators of rehabilitation facilities. Choices have to be made regarding the value of several outcome measurements as part of our conceptual framework of rehabilitation outcomes, which go beyond complications and survival. The outcomes of specific diagnosis groups should be clear to explain differences in performance of specialised rehabilitation departments.

Research on the process of reintegration in work

The Dutch legislation regarding work disability is complex and different from that of most other countries. Because of a large number of work-disabled people in The Netherlands several changes in legislation have been made in the last decade aiming at the increase of reintegration in work. In the first year of absence from work due to illness or injury, the employee receives full compensation of his salary based on the principles of the Sickness Benefit Act. During the first two years of absence from work due to illness or injury, both the employer and the employee are responsible for reintegration in work. The employer is obliged to support resumption of work or to offer an alternative job. At the end of the second year a decision of disablement can take place, either leading to continuation of employment with or without supplementary benefit from the Work Disability Act, or to termination of the employment. Benefit from the Work Dependent Act depends on the loss of earning capacity regarding employment that the employee can manage. Supplementary benefit from the Work Disability Act for the employee and a bonus for the number of disabled workers in the company for the employer, should make it more attractive for employers to keep disabled people employed.

Participation in the employment process of chronically disabled people has been an important point of political interest in The Netherlands in the last decade. However, many studies have shown that the chronically disabled still experience problems and are often insufficiently enabled to work[52-56]. *TNO Arbeid* (Dutch Organisation for Applied Scientific Research) has developed a research programme to evaluate the vocational situation of people with chronic diseases[55,56]. The main goal of this Vocational Handicap Research Programme was to describe the working conditions and experiences of chronically disabled people with various diagnoses, to create a more positive image of their capabilities and to improve reintegration care. People with SCI have not been involved in the programme yet. Recommendations to improve vocational outcome of disabled people found in international literature, were tailor-made educational and vocational

counselling, contact with peer groups, changing employer perceptions, improving transport and equal access, and reducing financial disincentives to working[33]. Most of these proceedings usually take place beyond the scope of the rehabilitation team. In her thesis, Schoppen emphasised the benefits of job modifications, specialised vocational rehabilitation programmes, and co-operation between all professionals involved in the process of reintegration of people with a leg amputation[57].

Aims of this thesis

Several issues in literature were important sources of inspiration for our research. At the outset of our study, little was known about the occurrence of spinal cord lesions and demographic characteristics of these patients in The Netherlands. Rehabilitation of patients with SCI is restricted to rehabilitation centres with a specialised department for spinal cord injury rehabilitation care. Acute medical care takes place in several hospitals. After the rehabilitation process people with SCI spread to various health care services. First of all, we aimed at an overview of characteristics of the Dutch population with SCI and describe the process of rehabilitation as part of the continuum of care for people with SCI in The Netherlands.

Secondly, more knowledge was needed about the actual outcomes of activities and participation according to the ICF in order to provide accurate prognostic information. This also includes neglected issues with huge social consequences, such as bladder and bowel care. As far as the level of participation is concerned, we lacked insight in the results of reintegration in society, as this largely takes place outside the scope of the rehabilitation team. Vocational reintegration of the chronically disabled is a topical subject and an important issue for people with SCI that should be studied extensively.

Thirdly, our attention was drawn to the role of personal factors of the individual patient and the subjective factors that influence the process of rehabilitation. Expectations of patients regarding functional outcome form an essential basis in the process of goal planning, and might be an important determinant of the rehabilitation outcome. In order to use rehabilitation services efficiently and involve patients in their rehabilitation process, the rehabilitation programmes should be based on realistic goals. Besides, we were interested in personal experiences, satisfaction and unmet needs of people with SCI after the process of rehabilitation and reintegration in society. With more knowledge about the factors interfering with a satisfying participation, the rehabilitation team can prepare patients and family and teach them how to cope with these matters.

Finally, information about external factors such as reintegration interventions and support from professionals was scarce and required attention. Aiming at optimal participation we have to know which

interventions promote adequate skills and strategies and create opportunities for participation.

The following objectives were formulated:

1. To give an epidemiological overview of the characteristics of a cohort of patients with spinal cord lesions and their process of rehabilitation;
2. To describe the outcome of independence in daily activities of patients with spinal cord injury at discharge from the rehabilitation centre, in relation to the early expectations of the rehabilitation team and the individual patient at admission;
3. To describe the outcomes of vocational and leisure participation, in relation to the patients' early expectations, reintegration interventions, current experiences, satisfaction and unmet needs, several years after the spinal cord injury.

Outline of this thesis

The first part includes this *introduction* on the main thrust of this thesis and an epidemiological overview of characteristics of the population under study. In *chapter 2* the incidence and general characteristics of a Dutch population with SCI are presented. Differences between traumatic and non-traumatic spinal cord lesions are indicated. An outline is given of several characteristics of the process of rehabilitation of patients with spinal cord lesions, admitted to a department specialised in SCI care of the rehabilitation centre. We discuss the benefits of regional care systems in the Dutch situation.

The second part focuses on the functional outcome after SCI at the level of activities and the prognosis of independence in daily activities based on early expectations of the individual patient and the rehabilitation team. In *chapter 3* a description is given of the neurological recovery and the functional outcome which is achieved during an inpatient rehabilitation period. Subgroups with different levels and extent of lesion are analysed regarding independence in self-care, ambulation and bladder and bowel care. In *chapter 4* the predictions of the professionals and the individual patient regarding functional outcome are compared to the number of patients who actually have achieved the expected level of independence at discharge from the rehabilitation centre.

The third part concentrates on aspects at the level of participation following a SCI. The process of reintegration in work is the studied (chapter 5), followed by the current experiences with work (chapter 6). The outcomes of participation and satisfaction with participation are presented (chapter 7). In *chapter 5* attention is paid to the role of early expectations the individual person with a SCI regarding return to paid work and other

indicators of success of job reintegration. An overview of the reintegration interventions is presented, including vocational training, job changes and adaptations. The barriers in the process of reintegration of persons who failed to return to work are mentioned. In *chapter 6* the vocational situation several years after the SCI is assessed. The results of job participation are related to the current health status and work-related disabilities. A description is given of the personal experiences, job satisfaction and unmet needs of those who are currently working. *In chapter 7* the changes in time use and actual reintegration in vocational and leisure activities are analysed several years after onset of the SCI. Results of life satisfaction will be presented, especially regarding the vocational and leisure situation. Reports are given of the support that is received during the reintegration process.

In the *general discussion and conclusions* the clinical and societal implications of this study are summarised and discussed. Recommendations for further research are given.

References

1. International Classification of Functioning, Disability and Health (ICF). Geneva: World Health Organisation, 2001.
2. Guttmann L. Spinal Cord Injuries. Oxford: Blackwell Scientific Publications, 1973.
3. Minaire P, Castanier M, Girard R, Berard E, Deidier C, Bourret J. Epidemiology of spinal cord injury in the Rhône-Alpes region, France 1970-75. Paraplegia 1978;16:76-87.
4. Garcia-Reneses J, Herruzo-Cabrera R, Martinez-Moreno M. Epidemiological study of spinal cord injury in Spain 1984 -1985. Paraplegia 1990;28:180-190.
5. Biering-Sorensen F, Pedersen V, Clausen S. Epidemiology of spinal cord lesions in Denmark. Paraplegia 1990;28:105-118.
6. Gjone R, Nordlie L. Incidence of traumatic paraplegia and tetraplegia in Norway: a statistical survey of the years 1974 and 1975. Paraplegia 1978;16:88-93.
7. Stover SL, Fine PR. The epidemiology and economics of spinal cord injury. Paraplegia 1987;25:225-228.
8. Shingu H, Ikata T, Katoh S, Akatsu T.Spinal cord injuries in Japan: a nationwide epidemiological survey in 1990. Paraplegia 1994;32:3-8.
9. Post MWM, Witte LP de, Asbeck FWA van, Dijk AJ van, Schrijvers AJP. Predictors of health status and life satisfaction in spinal cord injury. Arch Phys Med Rehabil 1998;78:395-402.
10. Waters RL, Adkins RH, Yakura JS, Sie I. Motor and sensory recovery following complete tetraplegia. Arch Phys Med Rehabil 1993;74:242-247.
11. Waters RL, Yakura YS, Adkins RH, Sie I. Recovery following complete paraplegia. Arch Phys Med Rehabil 1992;73:784-789.
12. Waters RL, Adkins RH, Yakura JS, Sie I. Motor and sensory recovery following incomplete paraplegia. Arch Phys Med Rehabil 1994;75:67-72.
13. Yarkony GM, Roth EJ, Heinemann AW, Wu Y, Katz RT, Lovell L. Benefits of rehabilitation for traumatic spinal cord injury. Arch Neurol 1987;44:93-96.
14. Woolsey RM. Rehabilitation outcome following spinal cord injury. Arch Neurol 1985;42:116-119.
15. DeVivo MJ, Kartus PL, Rutt RD, Stover SL, Fine PR. The influence of age at time of spinal cord injury on rehabilitation outcome. Arch Neurol 1990;47:687-691.
16. Lazar RB, Yarkony GM, Ortolano D et al. Prediction of functional outcome by motor capability after spinal cord injury. Arch Phys Med Rehabil 1989;70:819-822.

17. Yarkony GM, Roth EJ, Heinemann AW, Lovell L. Rehabilitation outcomes in C6 tetraplegia. Paraplegia 1988;26:177-185.
18. Rogers JC, Figone JJ. Traumatic quadriplegia: follow-up study of self-care skills. Arch Phys Med Rehabil 1980;61:- 316-321.
19. Welch RD, Lobley SJ,O'Sullivan SB, Freed MM. Functional independence in quadriplegia: critical levels. Arch Phys Med Rehabil 1986;67:235-240.
20. Mizukami M, Kawai N, Iwasaki Y et al. Relationship between functional levels and movement in tetraplegic patients. A retrospective study. Paraplegia 1995;33:189-194.
21. Hussey RW, Stauffer ES. Spinal cord injury: requirements for ambulation. Arch Phys Med Rehabil 1973;54:544-547.
22. Waters RL, Yakura JS, Adkins R, Barnes G. Determinants of gait performance following spinal cord injury. Arch Phys Med Rehabil 1989;70:811-818.
23. Nene AV, Hermens HJ, Zilvold G. Paraplegic locomotion: a review. Spinal Cord 1996;34:507-523.
24. Crozier KS, Ling Ling Cheng, Graziani V, Zorn G, Herbison G, Ditunno JF. Spinal cord injury: prognosis for ambulation based on quadriceps recovery. Paraplegia 1992;30:762-767.
25. Pentland W, Harvey AS, Smith T, Walker J. The impact of spinal cord injury on men's time use. Spinal Cord 1999;37:786-792.
26. Clayton KS, Chubon RA. Factors associated with the quality of life of long-term spinal cord injured persons. Arch Phys Med Rehabil 1994;75:633-638.
27. Siösteen A, Lundqvist C, Blomstrand C, Sullivan L, Sullivan M. The quality of life of three functional spinal cord injury subgroups in a Swedish community. Paraplegia 1990;28:476-488.
28. Goldberg RT, Freed MM. Vocational development of spinal cord injury patients: an 8-year follow-up. Arch Phys Med Rehabil 1982;63:207-210.
29. DeJong G, Branch LG, Corcoran PJ. Independent living outcomes in spinal cord injury: multivariate analyses. Arch Phys Med Rehabil 1984;65:66-73.
30. DeVivo MJ, Rutt RD, Stover SL, Fine PR. Employment after spinal cord injury. Arch Phys Med Rehabil 1987;68:494-498.
31. Murphy G, Brown D, Athanasou J, Foreman P, Young A. Labour force participation and employment among a sample of Australian patients with spinal cord injury. Spinal cord 1997;35:238-244.
32. Berghammer A, Gramm M, Vogler L, Schmitt-Dannert H-H. Investigation of the social status of paraplegic individuals after medical rehabilitation. Spinal cord 1997;35:493-497.
33. Conroy L, McKenna K. Vocational outcome following spinal cord injury. Spinal Cord 1999;37:624-633.

34. Tomassen PCD, Post MWM, Asbeck FWA van. Return to work after spinal cord injury. Spinal Cord 2000; 38:51-55.
35. Levi R, Hultling C, Seiger A. The Stockholm spinal cord injury study: 4. Psycho-social and financial issues of the Swedish annual level-of-living survey in SCI subjects and controls. Paraplegia 1996;34:152-157.
36. Krause JS. Employment after spinal cord injury. Arch Phys Med Rehabil 1992;73:163-169.
37. Noreau L, Dion S-A, Vachon J, Gervais M, Laramée M-T. Productivity outcomes of individuals with spinal cord. Spinal Cord 1999;37: 730-736.
38. Taricco M, et al. The social and vocational outcome of spinal cord injury patients. Paraplegia 1992;30:214-219.
39. Fugl-Meyer AR, Branholm I-B, Fugl-Meyer KS. Happiness and domain-specific life satisfaction in adult Northern Swedes. Clin Rehabil 1991;5:25-35.
40. Cushman LA. Spinal cord injury: 10 and 15 years after. Paraplegia 1992;30:690-6.
41. Eisenberg MG, Saltz CC. Quality of life among aging spinal cord injured persons: long term rehabilitation outcomes. Paraplegia 1991;29:514-520.
42. Fuhrer MJ, Rintala DH, Hart KA, Clearman R, Young ME. Relationship of life satisfaction to impairment, disability, and handicap among persons with spinal cord injury living in the community. Arch Phys Med Rehabil 1992;73:552-557.
43. Post MWM, Dijk AJ van, Asbeck FWA van, Schrijvers AJP. Life satisfaction of persons with spinal cord injury compared to a population group. Scand J Rehab Med 1998;30:23-30.
44. Asbeck FWA van. Functioneren met een paraplegie (thesis). Groningen: University of Groningen, 1987.
45. Witte LP de. After the rehabilitation centre: a study into the course of functioning after discharge from rehabilitation. Amsterdam/Lisse: Zwets & Zeitlinger, 1991.
46. Bennekom CAM van, Jelles F. Rehabilitation Activities Profile: the ICIDH as a framework for a problem-oriented assessment method in rehabilitation medicine (thesis). Amsterdam: Free University of Amsterdam, 1995.
47. Post M. Living with spinal cord injury (thesis). Utrecht: University of Utrecht, 1997.
48. International Classification of Impairments, Disabilities and Handicaps (ICIDH). Geneva: World Health Organisation, 1980.
49. Wade DT. Research into rehabilitation. What is the priority? Clin Rehabil 2001;15:229-232.
50. Wade DT. A framework for considering rehabilitation interventions. Clin Rehabil 1998;12:363-368.

51. Wade DT. Evidence relating to goal planning in rehabilitation. Clin Rehabil 1998;12:273-275.
52. Groothoff JW. Reïntegratie: ga terug naar af (official speech of inauguration). Groningen: University of Groningen, 2002.
53. Hoekstra EJ. Arbeidsbemiddeling met behulp van Supported Employment als interventie bij de reïntegratie van chronisch zieken (thesis). Groningen: University of Groningen, 2002.
54. Schoppen T, Boonstra AM, Groothoff JW, Vries J de. Göeken, LNH, Eisma WH. Employment status, job characteristics and work related health experience of people with lower limb amputation in the Netherlands. Arch Phys Med Rehabil 2001;82:239-245.
55. Andries F, et al. Vocational perspectives and neuromuscular disorders. International Journal of Rehabilitation Research 1997;20:255-273.
56. Wevers CWJ, Brouwer OF, Padberg GW, Nijboer ID. Job perspectives in facioscapulohumeral muscular dystrophy. Disability and Rehabilitation 1993;15:24-28.
57. Schoppen T. Functional outcome after a lower limb amputation (thesis). Groningen: University of Groningen, 2002.

Chapter 2

Rehabilitation of spinal cord lesions in The Netherlands: an epidemiological study

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Abstract

Very little is known about the occurrence of spinal cord lesions and results of rehabilitation in The Netherlands. This study was conducted to describe the process of rehabilitation treatment in the Dutch situation, to assess the incidence of spinal cord lesions in a regional rehabilitation centre and to characterise differences between traumatic and non-traumatic spinal cord lesions regarding age, level and extent of lesion.
In this study 293 patients were included who were admitted to the rehabilitation centre between 1982 and 1993. Sixty-six per cent of this group came from the university hospital. The mean length of stay in the rehabilitation centre was 154 days. After completing the rehabilitation programme 94% of patients went home. Sixteen new SCI patients per million per year were admitted to the rehabilitation centre. Of our group 52% had a non-traumatic lesion, which concerned older patients with more incomplete lesions.
In our opinion close collaboration between the university hospital and the rehabilitation centre is needed for optimal rehabilitation treatment. Attention to independent living programmes and appropriate housing facilities can shorten the length of stay and increase the number of discharges of patients to the own environment. For patients with non-traumatic spinal cord lesions special programmes should be made available.

Introduction

Spinal cord injury (SCI) leads to a fundamental change of life of the injured. It has many medical, emotional and social consequences for the patient, so multidisciplinary management is essential. SCI regional care systems have been established in a few countries[1,2,3]. In The Netherlands patients with acute SCI are admitted to traumatological, orthopedic, neurological and neurosurgical departments of university and general hospitals. As soon as the physical condition is stable they are transferred to one of the rehabilitation centres with a specialised department for spinal cord lesion care. If possible, patients go home after their inpatient rehabilitation period. In this study we investigated the leading role of the university hospital in taking care of SCI patients as a co-ordinating centre for a specific region. Length of stay in the rehabilitation centre was examined. Especially, we wanted to know the number of patients actually going to their home situation as being a goal of rehabilitation.

Many epidemiological studies present the incidence of SCI and analyse characteristics of the patients. Over the world the incidence of SCI varies from 9 to 53 per million inhabitants per year[4]. We will assess the incidence and characteristics of patients with SCI in the Dutch situation. International literature focuses on traumatic SCI. However, in European studies non-traumatic lesions form 25 to 39 per cent of all spinal cord lesions[5,6,7]. Characteristics of patients with non-traumatic spinal cord lesions differ from those with traumatic lesions. Analysis of these groups is also a subject of this study.

Methods

This retrospective study is based on data of 293 patients with spinal cord lesions admitted to the rehabilitation centre Beatrixoord in the period from 1982 to 1993. The SCI department accepts patients with acute and prolonged spinal cord lesions, who are suitable and motivated for a rehabilitation programme. A spinal cord lesion was defined as an acquired transverse lesion of the spinal cord and cauda equina, resulting in loss of motor and sensory function below the level of lesion and dysfunction of bladder and bowel[8,9]. Patients with systemic, demyelinative or degenerative diseases of the central nervous system, such as multiple sclerosis, and congenital diseases of the spinal cord, such as spina bifida, were excluded in this study. Patients with prolonged spinal cord lesions who had their first rehabilitation admission before 1982 or in another rehabilitation centre were also excluded. The data we obtained from the medical records include age, sex, neurological level and extent of the lesion, causes of SCI, hospital of origin, duration of hospitalisation of first admission and destination after discharge.

Revisions of the standards for neurological classification of spinal cord injured patients are made regularly by the American Spinal Injury

Association[10]. According to these standards we defined the neurological level of lesion as the most caudal intact segment of the spinal cord. The extent of the lesion was measured at the time of discharge. A complete lesion was defined as a SCI with no preserved motor or sensory function below the level of injury; an incomplete lesion as an injury with some motor and/or sensory function below the level of lesion. As collection of data started in 1982 we based our definitions on those of the American Spinal Injury Association of 1982[11].

Etiology of SCI was divided into traumatic and non-traumatic causes. Patients were transferred from university or general hospitals, mainly from the three northern provinces. Mean length of stay of 261 patients who completed the rehabilitation programme was determined. After discharge they went home or were transferred to a nursing home or to a semi-independent living situation.

Data analysis was done by SPSS/PC programme, descriptive statistics were used to characterise the study sample.

Results

Rehabilitation routing of SCI patients

Of 293 patients admitted to the rehabilitation centre after the acute phase 66% were referred from the Groningen University Hospital (GUH). The others came from smaller general hospitals in the northern provinces (26%) or other hospitals in the Netherlands (8%). From 1982 to 1993 there was no noticeable change in the number of GUH patients.

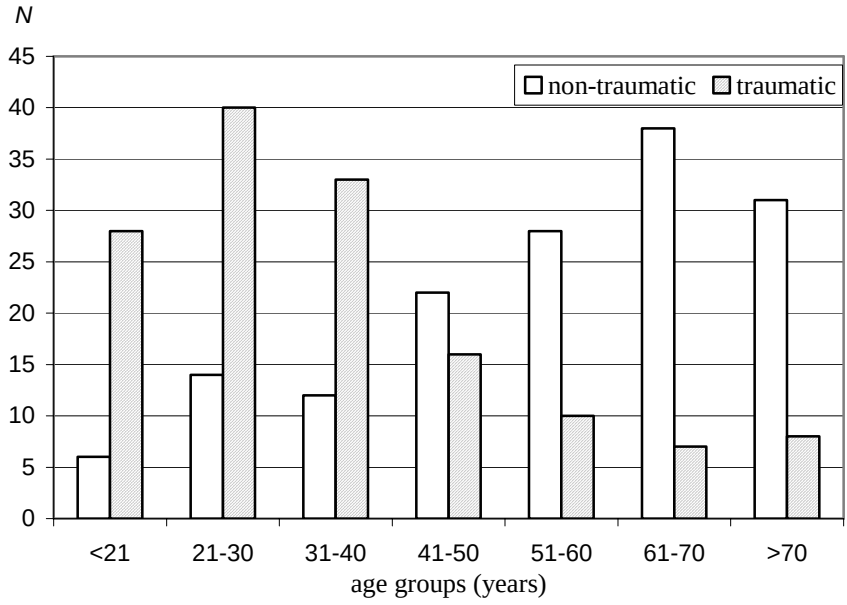
The characteristics of 193 patients from the university hospital were compared with those of 75 patients from the northern general hospitals. Patients from the GUH were on average younger with a mean age of 41.6 years as opposed to 56.2 years of patients from general hospitals. Patients younger than 40 years (n=117) had their acute phase of management after SCI in the university hospital in 89% of the cases, while 59% of patients older than 40 (n=151) were transferred from the GUH. The GUH group consisted of slightly more complete lesions (26% *versus* 19%). Patients with cervical lesions (n=108) came from the GUH in 69% of the cases, patients with lower lesions (n=160) in 74%. Patients with traumatic SCI (n=129) came from the GUH in 86% of the cases, patients with tumour (n=49) in 57%, with vascular causes (n=36) in 47% and with spinal degenerative causes (n=44) in 70% of the cases.

The length of first admission in the rehabilitation centre Beatrixoord after the onset of the spinal cord lesion varied from 1 day to 648 days. To determine the mean length of stay of the completed inpatient rehabilitation periods we excluded three patients who died, 11 patients who were admitted shorter than 8 days and 18 patients who were transferred to hospitals or other rehabilitation centres. Of the remaining 261 patients the mean length of stay was 154 days. There was a tendency that younger people stayed longer than

the older patients. Regarding sex there was no difference in length of stay. Complete cervical lesions led to the longest mean rehabilitation period of 296 days. The mean length of stay of patients with complete lesions was 244 days as opposed to 122 days for patients with incomplete lesions. Traumatic SCI led to an average admission of 205 days, while patients with myelopathies caused by tumour or degenerative changes of the spine stayed about 85 days. Six patients who went to semi-independent living situation stayed on average 312 days. There was no difference between patients who went home or who went to nursing homes (150 days).

In this period 261 patients completed their rehabilitation in our centre. Of this group 244 patients (94%) went home after the inpatient rehabilitation period. Eleven patients (4%) did not become independent enough to go home despite the intensive programme and went to nursing homes; three of them were younger then 40 years, two between 41 and 60 years of age and eight patients had cervical lesions. For six patients a place was found in a semi-independent living situation.

Figure 1. Distribution over age groups of patients with traumatic and non-traumatic spinal cord lesions (n = 293)



General characteristics
During twelve years 293 new cases of SCI were admitted to the rehabilitation centre. This means 16 new cases per million per year for a population of 1,5 million inhabitants. The male-female ratio was 2,2 : 1. The mean age at admission to the rehabilitation centre is 45.1 years. Most patients were in age groups 21 to 40 and 61 to 70 years (Figure 1). Regarding the level and extent of lesion 41% had a cervical lesion, 9% a complete cervical lesion. There was no noticeable trend in the number of cervical lesions during these 12 years.

Table 1. Characteristics of patients with non-traumatic spinal cord lesions as opposed to patients with traumatic lesions (*n*=293).

	Non-traumatic *n*=151		*Traumatic* *n*=142	
	n	%	*n*	%
Sex: Males	93	61.6%	109	76.8%
Females	58	38.4%	33	23.2%
Extent / level**:**				
Complete	20	13.2%	58	40.8%
- cervical	3	2.0%	24	16.9%
- thoracic	16	10.5%	29	20.4%
- lumbar/conus-cauda	1	0.7%	5	3.5%
Incomplete	131	86.8%	84	59.2%
- cervical	52	34.4%	42	29.6%
- thoracic	54	35.8%	16	11.2%
- lumbar/conus-cauda	25	16.6%	26	18.4%
Discharge:				
Premature	19	12.6%	10	7.1%
Nursing home	8	5.3%	3	2.1%
Semi-independent	4	2.6%	2	1.4%
Home	119	78.8%	125	88.0%

Traumatic versus non-traumatic spinal cord lesions
In our rehabilitation centre more than half of the population had a non-traumatic cause for the spinal cord lesion (52%). Of patients older than 40 years 74% had a non-traumatic cause and older than 60 years 81%. The non-traumatic group was on average older than the group with traumatic SCI with a mean age of 54.6 years as opposed to 35.0 years. The distribution over the age groups is shown in Figure 1. The male-female ratio was about 3 : 2 in the non-traumatic group as opposed to 3 : 1 in the traumatic group (Table 1). The non-traumatic group consisted of more patients with

incomplete lesions, 87% *versus* 59% in the traumatic group. Many of these patients with an incomplete non-traumatic lesion were in lower level groups, particularly mid-thoracic and low-thoracic lesions. The group with complete non-traumatic lesions was small (13%). Premature discharge to hospitals or nursing homes happened in 18% of those with non-traumatic lesions, especially when it concerned patients with tumours, and in 9% of traumatic lesions. Seventy-nine per cent of patients with non-traumatic lesions went home as opposed to 88% of the traumatic group.

Discussion

The concept of the comprehensive treatment of patients with spinal cord lesions is based on the concept that multidisciplinary treatment is essential for successful rehabilitation and the reintegration of the patient into society. Rehabilitation should not be separated from the initial treatment of SCI patients. In the USA a network of regional SCI care systems was established during the 1970s. In recent years it became clear that one of the benefits of regionalised centres is that they gain experience with the management of SCI[2]. Moreover, it leads to shorter lengths of stay, decrease of preventable complications and mortality, and reduction of costs[1,2,3]. In The Netherlands rehabilitation of spinal cord lesions is centralised in special departments of rehabilitation centres. Patients who are transferred to these departments come from different hospitals, as was found in this study. Of all patients admitted for the first time 66% came from the Groningen University Hospital. In our opinion regionalised SCI care systems should be set up in The Netherlands, consisting of a close collaboration between one hospital and a SCI rehabilitation centre. University hospitals should ideally treat patients in the acute phase, as they are already regional specialised trauma centres and cancer centres[12]. Rehabilitation medicine should be integrated with the treatment of patients with spinal cord lesions from the start.

Eighty-nine per cent of the study group completed the multidisciplinary rehabilitation programme in our centre. The mean length of stay of 154 days is comparable with the data from rehabilitation centres in Denmark and Japan[7,13]. The length of hospitalisation in the USA is much shorter with a mean duration below 100 days[1,2,14-16]. In contrast to the USA the Dutch National Health Service and private health insurances cover hospitalisation in a rehabilitation centre for an indefinite period. The average length of stay of patients with an incomplete SCI was shorter than of patients with complete SCI, despite the theory that patients who regain muscle strength usually require more intensive training to convert this improvements into functional abilities[17]. Discharge from the rehabilitation centre is very often delayed by social circumstances. A substantial number have to wait for suitable housing facilities[7], nursing homes and semi-independent institutions.

The aim of rehabilitation is to teach disabled persons to live with their disabilities in their own environment. In our population a high percentage of

patients (94%) went home after completing the programme. Only a few patients were transferred to nursing homes, because not enough care was provided in their home situation. In two American studies 95% of the patients were discharged to their own homes, in an other study 7% ended up in a nursing home[14,15,18]. Discharge to a nursing home often seems to fail for young SCI adults because of medical and psychosocial discongruences[18]. This should be an extra stimulus to provide training programmes concentrating on medical, personal and environmental factors, which determine the individual's ability to live independently after discharge[19]. Attention should be paid to appropriate housing, transportation, vocational aspects and leisure activities. Moreover, institutions for semi-independent living are needed with professional help in activities of daily living available on demand.

A reliable assessment of the incidence of spinal cord lesions in The Netherlands has not yet been done[20]. In European studies the incidence appears to be low (9 to 16/million/year). Most studies concentrate on traumatic SCI[5-8,21]. In the USA the annual rate was estimated to be between 30.0 and 32.1 new traumatic SCI patients per million persons in 1990[22]. The incidence of traumatic SCI is 39.4 per million per annum in Japan[4]. Variation in the incidence is explained by the definition of SCI and by sociological and demographic characteristics[23,24]. In our study we have taken into account that we based our figures on patients being admitted to the rehabilitation centre. We assume that nearly all patients with traumatic SCI are transferred to our centre and are registered. However, reliable registration of the group with non-traumatic lesions is not available, thus we can only give an estimation of the incidence (16 per million per year). This problem was also mentioned in another study[7].

All over the world young people of 20 to 40 years of age are most at risk of having a SCI. Vehicle accidents are the most important cause. The percentage of females is 20 to 28% of the total SCI population, regardless of aetiology. The mean age and the distribution of age of our patients is comparable with those found in other studies. The large number of females being admitted to the rehabilitation centre (31%) is remarkable. In comparison with male-female ratios in other studies this can be partly explained by the high number of non-traumatic lesions[7]. Social, economic and cultural dissimilarity also leads to variation in sex ratios[7,25]. The percentage of cervical lesions (41%) is similar to the percentage in other European countries, which varies from about 38% to 74%[4,6,7,22,23].

A large number of patients with non-traumatic spinal cord lesions was admitted to the SCI department of our rehabilitation centre. In studies regarding traumatic lesions, peaks are found in the younger age groups. Most patients with non-traumatic lesions, on the other hand, are 50 to 60 years of age[6,7]. The male-female ratio is about 4 : 1 for traumatic causes and 3 : 2 for the non-traumatic lesions[6,7]. Our results are consistent with those reported in other studies. Special programmes for these groups are needed based on

short inpatient rehabilitation treatment with realistic objectives. An assessment of the prognosis of functional outcome is necessary to prevent the disappointment of not completing the rehabilitation or not becoming independent enough to go home.

Conclusions

The purpose of this study was to give a epidemiological description of the process of rehabilitation, and the characteristics of a group of spinal cord lesion patients who were admitted to a Dutch rehabilitation centre. In our opinion the university hospital should ideally treat patients with spinal cord lesions in close collaboration with the rehabilitation centre. In this study 66% of the population came from the university hospital. The average length of stay in our centre was 154 days and 94% of the patients went home after discharge. It is important to focus our attention on independent living programmes and appropriate housing facilities to shorten length of stay and discharge even more patients to their own environment. Patients with non-traumatic lesions form half of the rehabilitation population and are distinguished by sex and age. We assume that special programmes with realistic objectives can provide better rehabilitation outcomes for those patients.

References

1. DeVivo MJ, Kartus PL, Stover SL, Fine PR. Benefits of early admission to an organised spinal cord injury care system. Paraplegia 1990;28:545-555.
2. Oakes DD, Wilmot CB, Hall KM, Sherk JP. Benefits of early admission to a comprehensive trauma center for patients with spinal cord injury. Arch Phys Med Rehab 1990;71:637-643.
3. Yarkony GM, Roth EJ, Meyer PR, Lovell L, Heinemann AW, Betts HB. Spinal cord injury care system: fifteen year experience at the rehabilitation institute of Chicago. Paraplegia 1990;28:321-329.
4. Shingu H, Ikata T, Katoh S, Akatsu T. Spinal cord injuries in Japan: a nationwide epidemiological survey in 1990. Paraplegia 1994;32:3-8.
5. Minaire P, Castanier M, Girard R, Berard E, Deidier C, Bourret J. Epidemiology of spinal cord injury in the Rhône-Alpes region, France 1970-75. Paraplegia 1978-79;6:76-87.
6. Garcia-Reneses J, Herruzo-Cabrera R, Martinez-Moreno M. Epidemiological study of spinal cord injury in Spain 1984 -1985. Paraplegia 1990;28:180-190.
7. Biering-Sorensen F, Pedersen V, Clausen S. Epidemiology of spinal cord lesions in Denmark. Paraplegia 1990;28:105-118.
8. Acton PA, Farley T, Freni LW, Ilegbodu VA, Sniezek JE, Wohlleb JC. Traumatic spinal cord injury in Arkansas, 1980 to 1989. Arch Phys Med Rehab 1993;74:1035-1040.
9. Kraus JF, Franti CE, Riggins RS, Richards D, Borhani NO. Incidence of traumatic spinal cord lesions. J Chron Dis 1975;28: 471-492.
10. Ditunno JF. New spinal injury standards, 1992. Paraplegia 1992;30:90-91.
11. American Spinal Injury Association. Standards for neurological classification of spinal injury patients. 1982, Chicago.
12. Arima T, Noguchi T, Mochida J, Toh E, Konagai A, Nishimura K Problems of long-term hospitalised cervical spinal cord injury patients in university hospitals. Paraplegia 1994;32:19-24.
13. Hasegawa Y, Ohasi M, Ando N, Hayashi T, Ishidoh T, Kumagai K, Shimazu A. Spinal cord injury hospitalisation in a rehabilitation hospital in Japan. Paraplegia 1994;32:47-51.
14. Gerhart KA. Spinal cord injury outcomes in a population-based sample. J of Trauma 1991;31:1529-1535.
15. DeVivo MJ, Rutt RD, Black KJ, Go BK, Stover SL. Trends in spinal cord injury demographics and treatment outcomes between 1973 and 1986. Arch Phys Med Rehab 1992;73:424-430.
16. Price C, Makintubee S, Herndon W, Istre GR.Epidemiology of traumatic spinal cord injury and acute hospitalization and

rehabilitation charges for SCI in Oklahoma, 1988 - 1990. Am J Epidemiology 1994;139:37-47.
17. Roth EJ, Lawler MH, Yarkony GM. Traumatic central cord syndrome: clinical features and functional outcomes. Arch Phys Med Rehab 1990;71: 18-23.
18. Weingarden SI, Graham P. Young spinal cord injured patients in nursing homes: rehospitalization issues and outcomes. Paraplegia 1992;30:828-833.
19. DeJong G, Branch LG, Corcoran PJ. Independent living outcomes in spinal cord injury: multivariate analyses. Arch Phys Med Rehab 1984;65:66-73.
20. Asbeck FWA van. Functioneren met een paraplegie (thesis). Groningen: University of Groningen, The Netherlands, 1987.
21. Gjone R, Nordlie L. Incidence of traumatic paraplegia and tetraplegia in Norway: a statistical survey of the years 1974 and 1975. Paraplegia 1978-79;16:88-93.
22. Stover SL, Fine PR The epidemiology and economics of spinal cord injury. Paraplegia 1987;25:225-228.
23. Lan C, Lai JS, Chang KH, Jean YC, Lien IN. Traumatic spinal cord injuries in the rural region of Taiwan: an epidemiological study in Hualien county, 1986-1990. Paraplegia 1993;31:398-403.
24. Chen CF, Lien IN. Spinal cord injuries in Taipei, Taiwan, 1978 - 1981. Paraplegia 1985;23:364-370.
25. Kuhn W, Zäch GA, Köchlin Ph, Urwyler A. Comparison of spinal cord injuries in females and in males, 1979-1981 Basle. Paraplegia 1983;21:154-160.

Chapter 3

Functional outcome of patients with spinal cord injury: rehabilitation outcome study

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Abstract

Objective: To increase our knowledge of neurological recovery and functional outcome of patients with spinal cord injuries in order to make more successful rehabilitation programmes based on realistic goals.
Design: Descriptive analysis of data gathered in an information system.
Setting: Rehabilitation centre in The Netherlands with special department for patients with spinal cord injuries.
Subjects: Fifty-five patients with traumatic spinal cord lesions admitted to the rehabilitation centre from 1988 to 1994.
Main outcome measures: The functional improvement was presented in terms of progress in independence in nine daily activity skills. Independence was rated on a four-point scale.
Results: From admission to discharge, lesions in 100% of patients with tetraplegia and 96% of patients with paraplegia remained complete. Significant progress in independence was made in self-care, ambulation and bladder and bowel care. Differences were found in the extent of functional improvement between subgroups of patients with different levels and extent of lesion. Contrary to expectations based on theoretical models, patients with complete paraplegia did not achieve maximal independence in self-care. Independent walking was only attained by patients with incomplete lesions. Regarding outcome of bladder and bowel care, poor results were found, especially the independence in defaecation and toilet transfers.
Conclusions: The results of this study provided more insight into the functional outcome of a group of patients with traumatic spinal cord injury. More research is needed to evaluate the rehabilitation programmes for these patients.

Introduction

Following the definitions set down by the World Health Organisation in 1980, the philosophy of rehabilitation is to reduce disabilities and handicaps resulting from impairments caused by trauma or disease[1]. Patients with spinal cord injuries (SCI) are confronted with motor and sensory deficits and dysfunction of bladder and bowel, leading to disabilities in activities of daily living[2]. The aim of rehabilitation is to teach patients with SCI how to achieve an optimal independent and satisfying lifestyle in their own community. Fortunately, most patients go home after rehabilitation and a significant number achieve functional independence[3-5].

To create successful rehabilitation programmes based on realistic goals, the prognosis of impairments, disabilities and handicaps should be clear. In recent years much attention has been paid to the neurological outcome after SCI. In several studies motor and sensory recovery following traumatic SCI has been quantified, based on the initial level of injury[6-8]. Most of the motor recovery occurs within the first six months after injury[6]. The degree of functional improvement, which is more relevant in predicting rehabilitation outcome, depends on the level and extent of lesion. Various theoretical models have been developed and studied to predict potential physical abilities based on spared motor and sensory functions[4,5,9-11]. However, other factors like age and motivation seem to be important too. Little systematic research is available concerning the number of patients who actually achieve the expected level of independence.

Many articles focus on self-care of patients with tetraplegia[12-14]. C6 and C7 are critical levels for achieving independence in daily activities[14]. Most authors agree that patients with paraplegia can achieve independence in self-care skills. Ambulation is the subject of several studies with a diversity of results[15-19]. The outcome of bladder and bowel care and incontinence of patients with spinal cord injuries is comparatively unknown.

This study gives an epidemiological description of the recovery of the impairments and disabilities of a group of spinal cord injury patients during an inpatient rehabilitation period. The functional improvement of these patients is presented in terms of progress in independence in daily activity skills. Subgroups with different levels and extent of lesion were analysed regarding independence in self-care, ambulation and bladder and bowel care. We compared our results with available information on expected independence in other studies.

Methods

In 1988 the Beatrixoord Rehabilitation Centre started with the assessment of medical and functional data of patients with SCI, who were registered in the Rehabilitation Information System - Information System for patients with

spinal cord injury (RIS-DIS). This information system was developed to evaluate the rehabilitation treatment of patients with a spinal cord injury in The Netherlands and to work out a prognostic model for functional outcome. The rehabilitation team (physician for rehabilitation medicine, nurse, physiotherapist, occupational therapist) provided detailed information about the medical and functional progress of those patients. Data were registered at six-weeks intervals following uniform instructions. In this study data were gathered at the first assessment after admission and the last before discharge from inpatient rehabilitation.

Data were obtained for 55 patients with traumatic SCI, consecutively admitted to the rehabilitation centre from 1988 to 1994. In order to describe the study group they were divided into four subgroups with different levels and extent of lesion, using the standards for neurological and functional classification developed by the American Spinal Injury Association (ASIA) in 1992[20,21]. According to these standards the neurological level of injury was defined as the most caudal segment of the spinal cord with normal motor function. Patients without function in the lowest sacral segment (complete lesions) at discharge form subgroups A and B. Subgroup A consisted of 10 patients with complete lesions at levels C4 to T1 (tetraplegia), subgroup B of 22 patients with lesions at levels below T1 (paraplegia). The patients with any motor or sensory function below the neurological level which included the lowest sacral segment (incomplete lesions) formed subgroup C (17 patients with lesions at C4 to T1) and D (six patients with lesions below T1).

To describe the disabilities of these patients nine relevant activities of daily living selected from the RIS-DIS were assessed . Self-care skills were feeding, upper body dressing and lower body dressing, either in bed or in chair. Ambulation consists of chair transfer, manual wheelchair propulsion and functional walking. Independent walking was defined as the ability to walk about 50 meters with or without assistant devices. Bladder and bowel care involved skills regarding bladder voiding, defaecation and toilet transfer. Continence for urine and bowels with or without the use of collection devices was assessed separately. Incontinence was defined as the unpredictable loss or spills of urine or faeces.

Independence was defined as the observed ability to perform an activity without help of another person (with or without appliance or orthosis). For all skills the degree of independence was rated on a four-point scale: independence 3 points, little assistance of another person 2 points, a lot of assistance 1 point and done by another person 0 points. The mean score per skill was 0 to 3 points. The mean score per set of three skills (self-care, ambulation and bladder and bowel care) was 0 to 9 points. These scores were calculated at admission and discharge and differences were examined by paired *t*-tests. Data analysis was carried out using SPSS/PC programme.

Results

General characteristics

The study population consisted of 47 males (85%) and eight females. Their age ranged from 16 to 73 years with a mean age of 33 years. All 55 patients had traumatic spinal cord lesions, which occurred in the period from 1988 to 1994. Twenty-five injuries (46%) were caused by traffic accidents, 11 (20%) by industrial accidents, nine (16%) were sport accidents of which four were caused by diving. There were two victims of violence (4%) and one patient attempted suicide. In the acute phase patients were admitted to university or general hospitals, where 39 (71%) of them underwent surgical interventions. Twelve patients (22%) were treated with traction or immobilization. The mean length of stay in hospital was 29 days (range 3 to 97 days). The mean stay in the rehabilitation centre was 254 days for the whole study group. Patients in subgroup A stayed on average 375 days, in subgroup B 250 days, in subgroup C 200 days, in subgroup D 220 days.

Neurological recovery

At admission 22 patients had an incomplete lesion. Of 33 patients with complete lesions 10 patients had lesions at or above T1. All those 10 patients kept complete lesions (subgroup A). Of 23 patients with complete lesions below T1 at admission 22 (96%) kept complete lesions (subgroup B).

Table 1. Independence rates of study group regarding nine activities of daily living at admission and discharge (maximum 3.0). Differences were examined by paired *t*-tests (*n*=57).

	Admission mean (SD)	*Discharge* mean (SD)	*Difference* *t*	*p*-value
Feeding	2.1 (1.0)	2.7 (0.6)	-4.8	*
Dressing UB	1.6 (1.2)	2.7 (0.6)	-7.5	*
Dressing LB	0.9 (1.1)	2.2 (1.1)	-8.1	*
Bed transfer	1.0 (1.1)	2.4 (1.1)	-9.2	*
Wheelchair	1.9 (1.3)	2.9 (0.4)	-5.9	*
Walking	0.3 (0.9)	1.0 (1.4)	-4.5	*
Bladder voiding	0.5 (1.2)	2.5 (1.2)	-9.7	*
Defaecation	0.4 (1.0)	1.6 (1.5)	-6.2	*
Toilet transfer	0.4 (0.9)	1.7 (1.4)	-6.8	*

* = $p < 0.01$

Functional improvement

Results of the whole study group regarding nine daily activities are presented in Table 1. Comparison of the independence rates at admission and at discharge showed a significant increase in independence for all skills.

Table 2 shows changes in independence of four different subgroups regarding self-care, ambulation and bladder and bowel care. Except for self-care in subgroup D and bladder and bowel care in subgroup A significant progress was made in independence in all subgroups.

Table 2. Independence rates of four subgroups regarding self-care, ambulation and bladder and bowel care at admission and discharge (maximum 9.0). Differences were examined by paired *t*-tests (*n*=57).

		Admission	*Discharge*	*Difference*	
	n	mean (SD)	mean (SD)	*t*	*p*-value
Self-care					
A	10	2.5 (2.0)	5.4 (2.5)	-5.1	0.001*
B	22	6.0 (2.3)	8.5 (1.1)	-6.2	0.000*
C	17	4.2 (2.7)	7.5 (1.7)	-5.1	0.000*
D	6	4.0 (3.6)	8.0 (2.4)	-3.2	0.025
Ambulation					
A	10	1.3 (1.3)	3.8 (1.5)	-5.5	0.000*
B	22	3.5 (1.5)	5.7 (1.2)	-7.7	0.000*
C	17	4.2 (3.4)	8.2 (1.6)	-4.9	0.000*
D	6	7.3 (3.0)	7.3 (2.4)	-5.3	0.003*
Bladder.and bowel care					
A	10	0.6 (1.3)	2.2 (2.9)	-1.9	0.091
B	22	0.9 (1.6)	4.3 (2.7)	-8.8	0.000*
C	17	2.8 (3.3)	7.9 (2.1)	-5.8	0.000*
D	6	0.5 (1.2)	7.0 (3.6)	-4.5	0.006*

* $p < 0.01$

Independence at discharge

Independence rates of eating warm meals, dressing upper and lower body at discharge are presented in Table 3. At discharge, eating and upper body dressing was done independently by patients in subgroup B; patients of subgroups C and D showed reasonable good results. Lower body dressing led to more dependence, especially in subgroup A.

Table 3. Independence rates of four subgroups regarding self-care at discharge (maximum 3.0) (*n*=57).

		Feeding		*Dressing UB*		*Dressing LB*	
	n	mean	(SD)	mean	(SD)	mean	(SD)
A	10	2.0	(0.8)	2.3	(0.9)	1.1	(1.0)
B	22	3.0	(0.0)	3.0	(0.2)	2.6	(1.0)
C	17	2.6	(0.5)	2.6	(0.6)	2.3	(0.8)
D	6	2.8	(0.4)	2.7	(0.8)	2.5	(1.2)

Table 4. Independence rates of four subgroups regarding ambulation at discharge (maximum 3.0) (*n*=57).

		Transfer		*Wheelchair*		*Walking*	
	n	mean	(SD)	mean	(SD)	mean	(SD)
A	10	1.1	(0.9)	2.7	(0.9)	0	(0)
B	22	2.7	(0.9)	3.0	(0.2)	0.1	(0.4)
C	17	2.8	(0.8)	3.0	(0.0)	2.5	(1.0)
D	6	2.5	(1.2)	3.0	(0.0)	1.8	(1.5)

Scores regarding transfers, manual wheelchair propulsion and walking are summarised in Table 4. Making transfers from bed to chair was done independently by most, but not all patients in subgroups B, C and D. Regarding wheelchair propulsion maximal scores were found in those subgroups and a submaximal score in subgroup A. Independent walking over 50 meters with or without assistant devices was achieved by 15 patients (27% of the whole study group), only patients with incomplete lesions.

Regarding bladder and bowel care, the majority of patients needed assistance with voiding and defaecation at admission to the rehabilitation centre. Results of independence at discharge are shown in Table 5. Thirty patients (55% of whole study group) proceeded with intermittent catheterisation, 35 (64%) with suprapubic tapping. Most patients in subgroups B, C and D achieved independence in those bladder voiding techniques. Scores of independence in defecation were low in subgroup A and B. Toilet transfer

caused more need for assistance than transfer from bed to chair. Scores for subgroup B were noticeably lower.

Incontinence
Reports about continence at discharge showed that four females (50% of females) were incontinent for urine. One had an indwelling catheter and two were to get a sacral root stimulator soon after discharge. One continent female already had electronic bladder control. Of 47 males 29 (61%) had unpredictable spills of urine and 27 were effectively helped with condom collecting bags. Six patients (11%) were incontinent for faeces, including two females who were also incontinent for urine.

Table 5. Independence rate of four subgroups regarding bladder and bowel care at discharge (maximum 3.0) (*n*=57).

		Bladder voiding		*Defaecation*		*Toilet transfer*	
	n	mean	(SD)	mean	(SD)	mean	(SD)
A	10	1.2	(1.5)	0.3	(0.9)	0.7	(0.9)
B	22	2.9	(0.6)	1.4	(1.5)	1.2	(1.5)
C	17	2.6	(1.0)	2.5	(1.8)	2.8	(0.7)
D	6	2.5	(1.2)	2.5	(1.2)	2.0	(1.5)

Discussion

The aim of this study was to describe the outcome of a group of patients with SCI. Although we realised that the number of patients was small, we considered it to be a representative group of patients with a traumatic spinal cord lesion in The Netherlands. We found some interesting trends which should have influence on the contents of the rehabilitation programme.

In order to determine the rehabilitation outcome, the functional outcome can not be studied independently of the neurological recovery. In this study we found little change in the extent of lesion during the rehabilitation period. Studies of Waters *et al.* revealed that of complete lesions assessed one month after injury, 90% of tetraplegia and 96% of paraplegia remained complete[6,7]. A one-month post-injury baseline was used, when an accurate examination can be performed as the patient is usually co-operative and acute complications have been resolved[6-7]. In this study the first neurological assessment after admission in the rehabilitation centre took place at on average 29 days after the SCI. Functional recovery was expressed in terms of progress in independence in activities of daily living. Yarkony *et al.* reported that functional improvement

after SCI is expected to occur most rapidly during inpatient rehabilitation due to spontaneous neurological recovery, intensity of training and a multidisciplinary approach of problems[4,22]. We found that the study group became significantly more independent in self-care, ambulation, as well as bladder and bowel care. To what extent the rehabilitation programme was responsible for the changes, can not be demonstrated with this study design. However, we also found that patients with permanent complete lesions (subgroups A and B) showed substantial functional improvement.

The functional outcome of tetraplegia has received considerable attention in the literature. The functional motor recovery of the upper extremities of tetraplegics determines final independence in activities of daily living[14]. Regarding the results of patients with complete tetraplegia of subgroup A, we found a high independence score for wheelchair propulsion at discharge. Some of this group became able to eat and dress upper body independently. Training these skills should be an important item on the rehabilitation programme. Nearly all patients of subgroup A remained dependent on assistance in dressing lower body, ambulation and bladder and bowel care. Progress in these skills was not significant and training does not seem very successful.

Most authors agree that patients with levels lower than C7 should be able to accomplish most daily living skills independently, except walking[5,14]. The functional performance of those patients also depends on other factors, like co-morbidity, age, spasticity, motivation and coping[9-11]. Patients with complete lesions below T1 (subgroup B) did not achieve maximal independence in dressing lower body, making transfers and bladder and bowel care. Results of defecation and toilet transfer were poor: even some patients with lesions at lumbar levels did not achieve full independence. Although the results of rehabilitation were encouraging, the functional outcome of this group was not as good as expected based on the theoretical models. This is an important finding if we want to be realistic about the prognosis of patients with complete paraplegia.

Patients with incomplete lesions of subgroups C and D showed reasonably high scores overall. However, it was noted that patients with incomplete paraplegia showed more disabilities in self-care and bladder and bowel care than indicated by their theoretical potential. Impaired hand function might have played a role in some patients with incomplete tetraplegia.

Ambulation has been extensively studied in patients with spinal cord injuries[15-19]. Nene *et al.* present a review of reports concerning locomotion[18]. There is considerable difference in opinion regarding a patient's ability to walk and the use of orthoses. In this study, patients with complete paraplegia were not able to walk independently over 50 meters. Although the level of lesion does not seem to be very important, by most authors it is generally accepted that patients with complete lesions above T10 are unsuitable for functional locomotion. A diversity of results in those studies is based on major differences in definition and study population. This makes it difficult to compare our results with other studies.

Studies do not often focus on independence in bladder and bowel care. As many patients with SCI do not become continent, it is important that they achieve optimal independence in care in order to prevent incontinence as much as possible. We found poor results, which means that most patients remain dependent on help. In order to reduce the psychosocial consequences, bladder and bowel care should form an important part of the rehabilitation programme. Advances in urological pharmacology and sacral root stimulators may lead to better results in future studies[23,24,25].

References

1. International Classification of Impairments, Disabilities and Handicaps. World Health Organisation, Geneva, 1980.
2. Ditunno Jr JF, Young W, Donovan WH, Creasey G. The International Standards Booklet for Neurological and Functional Classification of Spinal Cord Injury. Paraplegia 1994;32:70-80.
3. Schönherr MC, Groothoff JW, Mulder GA, Eisma WH. Rehabilitation of patients with spinal cord lesions in the Netherlands: an epidemiological study. Spinal Cord 1996;34:679-683.
4. Yarkony GM, Roth EJ, Heinemann AW, Wu Y, Katz RT, Lovell L. Benefits of rehabilitation for traumatic spinal cord injury. Arch Neurol 1987;44:93-96.
5. Woolsey RM. Rehabilitation outcome following spinal cord injury. Arch Neurol 1985;42:116-119.
6. Waters RL, Adkins RH, Yakura JS, Sie I. Motor and sensory recovery following complete tetraplegia. Arch Phys Med Rehabil 1993;74:242-247.
7. Waters RL, Yakura YS, Adkins RH, Sie I. Recovery following complete paraplegia. Arch Phys Med Rehabil 1992;73:784-789.
8. Waters RL, Adkins RH, Yakura JS, Sie I. Motor and sensory recovery following incomplete paraplegia. Arch Phys Med Rehabil 1994;75:67-72.
9. Yarkony GM, Roth EJ, Heinemann AW, Lovell L. Spinal cord injury rehabilitation outcome: the impact of age. J Clin Epidemiol 1988;41:173-177.
10. DeVivo MJ, Kartus PL, Rutt RD, Stover SL, Fine PR. The influence of age at time of spinal cord injury on rehabilitation outcome. Arch Neurol 1990;47:687-691.
11. Lazar RB, Yarkony GM, Ortolano D et al. Prediction of functional outcome by motor capability after spinal cord injury. Arch Phys Med Rehabil 1989;70:819-822.
12. Yarkony GM, Roth EJ, Heinemann AW, Lovell L. Rehabilitation outcomes in C6 tetraplegia. Paraplegia 1988;26:177-185.
13. Rogers JC, Figone JJ. Traumatic quadriplegia: follow-up study of self-care skills. Arch Phys Med Rehabil 1980;61:316-321.
14. Welch RD, Lobley SJ,O'Sullivan SB, Freed MM. Functional independence in quadriplegia: critical levels. Arch Phys Med Rehabil 1986;67:235-240.
15. Mizukami M, Kawai N, Iwasaki Y et al. Relationship between functional levels and movement in tetraplegic patients. A retrospective study. Paraplegia 1995;33:189-194.
16. Hussey RW, Stauffer ES. Spinal cord injury: requirements for ambulation. Arch Phys Med Rehabil 1973;54:544-547.

17. Waters RL, Yakura JS, Adkins R, Barnes G. Determinants of gait performance following spinal cord injury. Arch Phys Med Rehabil 1989;70:811-818.
18. Nene AV, Hermens HJ, Zilvold G. Paraplegic locomotion: a review. Spinal Cord 1996;34:507-523.
19. Crozier KS, Ling Ling Cheng, Graziani V, Zorn G, Herbison G, Ditunno JF. Spinal cord injury: prognosis for ambulation based on quadriceps recovery. Paraplegia 1992;30:762-767.
20. ASIA/IMSOP. Standards for Neurological and Functional Classification of Spinal Cord Injury - Revised 1992. American Spinal Injury Association, Chicago, 1992.
21. Waters RL, Adkins RH, Yakura JS. Definition of complete spinal cord injury. Paraplegia 1991;29:573-581.
22. Yarkony GM, Roth EJ, Heinemann AW, Lovell L, Wu Y. Functional skills after spinal cord injury rehabilitation: three-year longitudinal follow-up. Arch Phys Med Rehabil 1988;69:111-114.
23. Wyndaele JJ. Development and evaluation of the management of the neuropathic bladder. Paraplegia 1995;33:305-307.
24. Timoney AG, Shaw PJR. Urological outcome in female patients with spinal cord injury: the effectiveness of intermittent catheterisation. Paraplegia 1990;28:556-563.
25. Brindley GS. The first 500 patients with sacral anterior root implants. Paraplegia 1994;32:795-805.

Chapter 4

Prediction of functional outcome after spinal cord injury: a task for the rehabilitation team and the patient

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Abstract

Study design: Descriptive analysis of data gathered in an information system.
Objectives: To explore the predictions of professionals and patients regarding functional outcome after a spinal cord injury, related to the final results after inpatient rehabilitation, in order to make prognostics of rehabilitation outcome more successful and enlarge the role of the patient in selecting realistic rehabilitation goals.
Methods: Data of 55 patients with spinal cord injuries admitted to the rehabilitation centre. Expectations of the rehabilitation team and the patients regarding future independence in performing six daily activities were compared to the functional results at discharge. The results of patients with different level and extent of lesion were analysed.
Results: In 52% of all performed skills independence was achieved at discharge. Professionals and predicted made similar predictions. If they both expected independence after rehabilitation, 90% of the skills were performed independently at discharge. If they both did not expect independence, only 3% of the functional results were positive. Of all combined predictions 64% was correct. Correct predictions were most often found regarding self-care skills of patients with paraplegia and regarding mobility of patients with complete lesions. Prediction of self-care outcome of patients with tetraplegia is far more complicated. There was considerable variation in the predictions of mobility potential, especially regarding patients with incomplete lesions. If the team and patients agreed upon expected independence in mobility skills of these patients, the final results were mostly positive.
Conclusions: Prediction of functional outcome after spinal cord injury was most successful if the expectations of the team and patients were combined. Prognosis of self-care outcome of patients with paraplegia and mobility potential of patients with complete spinal cord lesions was usually clear at admission. However, selection of realistic goals concerning self-care skills of patients with tetraplegia and mobility skills of patients with incomplete lesions is far more complicated. Gradual adjustment of objectives is needed during the rehabilitation process in close collaboration between the professionals and the patients.

Introduction

Soon after their accident patients with spinal cord injuries (SCI) are confronted with motor and sensory deficits and bladder and bowel dysfunction of which the consequences for daily living are uncertain. Early prediction of neurological recovery and functional abilities after rehabilitation is essential to inform the patient and to make plans for treatment. Several studies focused on neurological and functional outcome after spinal cord lesions[1-6.] However, studies that actually evaluate functional prognosis are rare[4] and expectations of patients were never examined, as far as we know. This study was conducted to explore the predictions of both the professionals and the patients regarding functional outcome, related to the final results after the rehabilitation.

In the acute phase, prognosis is usually based on the neurological status and early restoration of motor and sensory functions. In several studies motor and sensory recovery after traumatic SCI was quantified based on the initial neurological level of injury[1-3]. To select realistic goals and involve patients in their rehabilitation process, information about the prognosis of the functional outcome is indispensable[4,7]. Prediction of functional potential is most realistic after 30 days, when major changes in neurological status have taken place[1]. In general, we base our prognosis of functional outcome on the level and extent of lesion. Theoretical models are developed to predict potential physical abilities[4,5,7-9]. Little is known about the actual number of patients who achieve this theoretical level of independence. Other factors such as age, weight, co-morbidity, spasticity, coping strategies and motivation also seem to play an important role[4-6,8,10,11]. According to their physical potential most patients with paraplegia can achieve independence in self-care skills[4]. There is a considerable difference in opinion regarding the patient's ability to walk independently[12].

Many patients with spinal cord injuries are able to go home after the rehabilitation period and a significant number achieve a reasonable degree of independence in the performance of daily living skills[4-6,13]. Quality of life is more difficult to predict and mainly determined by effective adjustment to the changes after the injury.

We were interested to see if the expectations of professionals and patients concerning functional outcome were realistic. In this study the predictions of independence in self-care and mobility skills assessed soon after admission were related to the functional status at discharge. In order to explore the role of the patients, we compared their predictions with those of the professionals. Combinations of predictions of both the team and patients were studied. Differences in predicting outcome of patients with complete and incomplete tetraplegia and paraplegia were analysed.

Methods

This retrospective study was based on the data of 55 patients with acute traumatic spinal cord injury who were admitted to Beatrixoord Rehabilitation Centre from 1988 to 1994. The SCI department treats patients with acute and prolonged SCI, and patients with other severe injuries and non-traumatic diseases of the spinal cord. Data were registered in the Rehabilitation Information System - Information System for patients with spinal cord injury (RIS-DIS). This information system was developed to evaluate the rehabilitation treatment of patients with a spinal cord injury and to work out a prognostic model for functional outcome. Four members of the rehabilitation team (physician for rehabilitation medicine, nurse, physical therapist and occupational therapist) provided detailed information about the medical and functional course of patients from admission to discharge following uniform instructions.

At 8 weeks after admission the rehabilitation team was asked to predict the functional status of individual patients with acute SCI regarding several daily activities. The medical and psychosocial situation of the patient was taken into account. Questions were asked such as ”Do you expect that the patient will eat independently?”, ”Do you expect that the patient will walk independently?” etcetera. Possible answers were ”yes”, ”no” and ”uncertain”. The rehabilitation team reported ”yes” or ”no”, if all members agreed upon the expectation. If an unanimous prediction was not available, ”uncertain” was recorded.

At the same time each patient also filled in this questionnaire assisted by the social worker, neither being informed about the answers of the team. The patient followed a standard rehabilitation programme from the first day after admission including education and training.

For this study the following were used: (1) the predictions reported by the team and the patients 8 weeks after admission and (2) the functional results registered in the RIS-DIS assessed by the occupational therapist at discharge. Functional outcome was expressed in terms of independence in the six activities of daily living. Of all functional activities in the RIS-DIS we selected eating, upper body dressing and lower body dressing (self-care), walking, stair climbing and making a car transfer (mobility). Independence was defined as the observed ability to perform an activity without the help of another person (with or without appliance or orthosis). Independent walking was defined as the ability to walk about 50 meters with or without devices. The therapist who assessed the functional results was blinded from the expectations at admission. Data of functional status at discharge of all patients were present. Predictions of the rehabilitation team were missing in three cases, predictions of the patients in two cases and of both the rehabilitation team and patients in six cases. All 11 cases were left out of the study.

In order to discriminate for level and extent of lesion the study group was divided into four subgroups: (1) complete tetraplegia; (2) complete paraplegia; (3) incomplete tetraplegia and (4) incomplete paraplegia. According to the

standards for neurological and functional classification by the American Spinal Cord Association of 1992, the neurological level was defined as the most caudal segment of the spinal cord with normal function[14]. A complete lesion implies that the patient has no function below the neurological level including the lowest sacral segment. All lesions that were complete at admission remained complete during the course.

For the analysis of age as a discriminating factor we divided the population into groups: (1) below 30 years of age, and (2) 30 years and older. We differentiated between spasticity of upper and lower extremities, spasticity of lower extremities and no spasticity at all. Data analysis was done by the SPSS/PC programme.

Results

The study group consisted of 55 patients with a spinal cord injury of which 11 cases were left out because data of predictions were missing. This group consisted of seven patients with an incomplete tetraplegia, who were almost fully independent and able to walk soon after admission. They were often discharged before assessment of predictions regarding future abilities took place. One patient was unable to answer the questions because of poor knowledge of Dutch. The remaining group of 44 patients included six females and 38 males. Their age ranged from 16 to 73 years with a mean of 32 years. Half of the injuries were caused by traffic accidents. Twenty-eight patients (64%) underwent surgical interventions and ten patients (23%) were treated with traction or long-term immobilisation. The mean length of stay in hospital in the acute phase was 28 days. The stay in the rehabilitation centre lasted on average 270 days (range 107 to 514 days). Ten patients had complete tetraplegia, 18 patients complete paraplegia, 11 patients incomplete tetraplegia and five patients had incomplete paraplegia.

In Table 1 the predictions of the rehabilitation team are compared with those of the patients and we found that 140 (53%) *versus* 147 (56%) ”yes” answers were given and 73 (28%) *versus* 76 (29%) ”no” answers. We found 51 (19%) ”uncertain” answers given by the team and 41 (16%) by the patients. The team was more reserved in predicting results of self-care skills and making car transfers. The patients were more uncertain about the independence in stair climbing. ”Uncertain” expectations of independence in walking were equal in both groups.

Of 140 activities in which independence was predicted by the team 119 of 140 (85%) results were positive compared to 120 of 147 (82%) positive results predicted by the patients. When the team and patients did not expect independence, in only four of 73 (5%) respectively three of 76 activities (4%) positive results were achieved. These differences were not significant. In 138 of all 264 performed activities (52%) independence was achieved at discharge. Upper body dressing was performed independently in 80% of the

patients and independence in eating was found in 68% of patients. One out of four patients was able to walk independently at discharge.

Table 1. Predictions of the rehabilitation team and patients regarding independence in different activities of daily living related to number and percentage of positive results in performing activities independently at discharge (*n*=44).

Activities of daily living	*Predictions*	*Rehabilitation team*			*Patients*		
		n	pos	%	*n*	pos	%
Eating	Yes	32	26	81	34	28	82
	No	2	0	0	3	1	33
	Uncertain	10	4	40	7	1	14
	Total	44	30	68	44	30	68
Upper body dressing	Yes	38	32	84	38	34	89
	No	1	0	0	3	0	0
	Uncertain	5	3	60	3	1	33
	Total	44	35	80	44	35	80
Lower body dressing	Yes	26	23	88	28	21	75
	No	3	0	0	6	0	0
	Uncertain	15	4	27	10	6	60
	Total	44	27	61	44	27	61
Car transfer	Yes	30	26	87	32	25	78
	No	3	0	0	5	0	5
	Uncertain	11	2	18	7	3	43
	Total	44	28	64	44	28	64
Walking	Yes	7	6	86	8	6	75
	No	28	3	11	27	1	4
	Uncertain	9	2	22	9	4	44
	Total	44	11	25	44	11	25
Stair climbing	Yes	7	6	86	7	6	86
	No	36	1	3	32	1	3
	Uncertain	1	0	0	5	0	0
	Total	44	7	16	44	7	16
Total	Yes	140	119	85	147	120	82
	No	73	4	5	76	3	4
	Uncertain	51	15	29	41	15	37
	Total	264	138	52	264	138	52

In Table 2 identical predictions of the rehabilitation team and patients concerning six activities of daily living were combined. Of 264 combined answers we found 123 (47%) both ”yes”-combinations, meaning that both the team and the patient expected independence and 59 (22%) both ”no”-combinations with unanimous negative expectations. Of the both ”yes”-combinations 111 of 123 (90%) were correct, meaning that they were in accordance with the final results. Of the 59 both ”no”-combinations 57 (97%) were correct. Of these 182 identical predictions 168 (92%) were correct, which was 64% of all 264 combinations. Regarding the six different activities we found high percentages of correct answers in upper body dressing and stair climbing (respectively 75 and 80% of combinations), while a lower percentage was found in lower body dressing (48%). In 82 combinations the team and the patients did not agree or were both uncertain. These categories of combinations were analysed in Table 3.

Table 2. Combinations of identical predictions of the rehabilitation team and patients regarding independence in different activities of daily living with number and percentage of correct predictions (*n*=44).

Activities of daily living	*Total comb. pred*	*Both yes*			*Both no*			*Total both yes and no*			
	n	*n*	corr.	%	*n*	corr.	%	*n*	corr.	%	% of total
Eating	44	28	25	89	1	1	100	29	26	90	59
Upper body dressing	44	36	32	89	1	1	100	37	33	89	75
Lower body dressing	44	21	19	90	2	2	100	23	21	91	48
Car transfer	44	25	23	92	3	3	100	28	26	93	59
Walking	44	7	6	86	22	21	95	29	27	93	61
Stair climbing	44	6	6	100	30	29	97	36	35	97	80
Total	264	123	111	90	59	57	97	182	168	92	64
% of total		47%			22%			69%			

In Table 3 all combinations of predictions of team and patient are presented related to the percentage of cases in which the patient actually performed the activities independently (percentages of success). Most independence was found when both the team and the patients expected this (111/123 = 90%). When either the team or the patient answered ”yes” 17 of 40 (43%) results were positive. In the category with other combinations (both ”uncertain” or ”no”/ ”uncertain”) in eight of 42 activities (19%) independence was achieved.

When the team and patients both did not expect independence only two of 59 (3%) results were positive.

Table 3. Combinations of predictions of the rehabilitation team and patients regarding independence in different activities of daily living related to number and percentage of positive results in performing these activities independently at discharge (*n*=44).

Activities of daily living	*Total comb. pred.*	*Both yes*			*One yes*			*Other combinations*			*Both no*		
	n	*n*	pos	%	*n*	pos	%	*n*	pos	%	*n*	pos	%
Eating	44	28	25	89	10	4	40	5	1	20	1	0	0
Upper body dressing	44	36	32	89	4	2	50	3	1	33	1	0	0
Lower body dressing	44	21	19	90	12	6	50	9	2	22	2	0	0
Car transfer	44	25	23	92	11	5	45	5	0	0	3	0	0
Walking	44	7	6	86	1	0	0	14	4	29	22	1	5
Stair climbing	44	6	6	100	2	0	0	6	0	0	30	1	3
Total	264	123	111	90	40	17	43	42	8	19	59	2	3

We compared self-care and mobility outcome of patients of four subgroups with different level and extent of lesion (Table 4). Regarding the self-care skills of patients with paraplegia both the team and patients expected independence of nearly all patients. All those patients achieved independence in eating and dressing the upper body. Lower body dressing was not always predicted correctly and only two of the 23 patients were not independent at discharge. Predictions of self-care outcome of patients with tetraplegia varied strongly. About 40% of the activities were performed independently (25 of 63).

Regarding the mobility skills of patients with complete lesions the team and patients often agreed about the expected negative results of walking and stair climbing. Predictions of making car transfers showed a lot of variation in answers, while only one patient with complete tetraplegia and 13 with complete paraplegia achieved independence at discharge. Concerning functional walking of patients with complete paraplegia we found that seven out of 18 combinations were ”other combinations”, which means that the team and patients did not agree or were both uncertain. The results at discharge of this group were poor.

If we focus on the mobility predictions of patients with incomplete lesions, we also found various combinations of predictions. If the team and patients both expected independence, the success percentage was high. One patient with incomplete tetraplegia became independent in walking and stair climbing, although both the team and the patient himself did not expect functional ambulation soon after admission.

Discrimination for age and degree of spasticity did not influence the results in any way.

Table 4. Combinations of predictions of rehabilitation team and patients regarding independence of 4 subgroups with patients with different level and extent of lesion related to the percentage of positive results in performing different activities of daily living (*n*=44).

Subgroups	*Predictions*	*Eating*		*Upper body dressing*		*Lower body dressing*		*Car transfers*		*Walking*		*Stair climbing*	
		n	*pos*	*n*	*pos*	*n*	*pos*	*n*	*pos*	*n*	*pos*	*n*	*pos*
Complete tetraplegia *n*=10	Both yes	3	33	5	80	0		0		0		0	
	One yes	2	0	3	33	2	50	4	25	0		0	
	Other comb	4	25	1	100	7	0	4	0	1	0	1	0
	Both no	1	0	1	0	1	0	2	0	9	0	0	
Incompl tetraplegia *n*=11	Both yes	3	67	9	67	4	75	7	100	5	100	5	100
	One yes	7	43	0		4	0	3	100	1	0	0	
	Other comb	1	0	2	0	2	100	0		3	67	3	0
	Both no	0		0		1	0	1	0	2	50	3	33
Complete paraplegia *n*=18	Both yes	17	100	17	100	14	95	15	87	1	0	0	
	One yes	1	100	1	100	4	75	2	0	0		1	0
	Other comb	0		0		0		1	0	7	0	2	0
	Both no	0		0		0		0		10	0	0	
Incompl paraplegia *n*=5	Both yes	5	100	5	100	3	100	4	75	1	100	1	100
	One yes	0		0		2	100	1	100	0		1	0
	Other comb	0		0		0		0		3	67	0	
	Both no	0		0		0		0		1	0	3	0

Discussion

The importance of early prediction of neurological and functional outcome of spinal cord injury is frequently stressed[1,4,7]. Prognosis of neurological recovery and functional abilities is useful in informing the patient and his family and making decisions about treatment. Forecasting length of stay, costs and equipment is not possible without this information[7].

Prognosis of neurological recovery is based on neurological examinations in the acute phase. As patients are unconscious, uncooperative or in pain, this

information is often not reliable[1]. During the first days after the spinal cord injury both neurological improvement and regression can be seen, due to post-injury changes in the spinal cord or surgical and medical intervention[14]. In an attempt to perform a more accurate assessment in the acute period, other methods are being studied such as motor and somato-sensory evoked potentials[16].

When patients have recovered from acute medical problems rehabilitation plans are made based on the prognosis of future functional abilities. Even when neurological recovery is small, especially of patients with complete lesions, the functional improvement in daily activity skills is usually substantial[6]. Besides level and extent of lesion other factors play an important role in functional prognosis[4-6,8,10,11]. Age, weight, co-morbidity are prognostic indicators which are largely known from the start of rehabilitation. Influence of factors such as spasticity, pain, motivation and psychosocial factors becomes clear in later phases. During inpatient rehabilitation maximal outcome is gained by intensive training of functional skills and multidisciplinary approach of problems[17]. In order to use rehabilitation services efficiently rehabilitation programmes should be based on selected realistic goals.

Several studies focused on the functional outcome of patients with spinal cord injury[4-6]. Predictions of the potential functional status are more reliable when they are founded on extensive multidisciplinary examination, including assessment of psychosocial circumstances[5] Few studies actually dealt with the correlation between predictions and final outcome after rehabilitation[4]. This is the first study in which the predictions of patients were also used.

All patients in this group followed a complete rehabilitation programme. Given the retrospective character of the study, both the professionals and the patients were not aware of scientific purposes at the time of treatment. It was not possible to treat patients blinded from the reported predictions, as confrontation with (discrepancy in) these expectations was part of the rehabilitation programme. However, patients were able to train all functional skills in consultation with the team, even if the team did not expect a positive result. Unfortunately the data of eleven patients were not complete. At least part of this group recovered so quickly that discharge took place before assessment of predictions. The results of functional prognosis and outcome of the total group of 55 patients were probably better than our actual results.
In selecting the functional abilities we were dependent on the items in the RIS-DIS and assessment list of predictions. Questions concerning bladder and bowel care did not match with the functional data of skills concerning bladder voiding and defaecation. The six skills studied here were considered as the most essential skills in self-care and mobility at home and outdoors.

When we looked at the results of the professionals and the patients we found that the similarity in predicting outcome was remarkable. The team and the patients recorded about equal numbers of ”yes”- and ”no”-answers. The rehabilitation team related the first impression of the individual patient after some weeks of training to their experience in treating patients with spinal cord

injury. Factors such as age, co-morbidity, spasticity and motivation were taken into account. If the opinions of the team were divided, ”uncertain” was noted. This might be an explanation for the higher number of ”uncertain” answers (19%) of the team. The predictions of the patients were based on the progress that was made so far in the standard programme of training and the information about prognosis received from the professionals. We assume that their expectations were influenced by subjective factors such as understanding and coping. When we compare the 73 negative predictions of the team and 76 of the patients with the 126 negative results, we have to conclude that both the team and the patients were inclined to be ”uncertain” instead of giving a negative answer, if independence was not expected. In our experience it can be useful to confront the patient with the disagreement in expectations, but it is important to know that the team did not predict outcome significantly better.

In on average two-thirds of the cases (69%), the patients and the team had unanimous predictions ”yes” or ”no”, of which most (92%) were correct. It appeared that the combination of predictions of both the team and the patients gave the most reliable prognosis. If they both predicted independence, 90% of the activities were performed independently compared to 85% respectively 82%, if we only used the separate expectations of the team and the patients. If they both did not expect independence only 3% of the final results were positive. This was not different from the percentage of correct separate negative predictions of the team and patients. Most agreement and the highest number of correct predictions were found for upper body dressing. In contradiction, results for lower body dressing were worse. In selecting goals for self-care it is important to be aware of these discrepancies.

Regarding the self-care outcome of patients with paraplegia we found a lot of agreement on the expected degree of independence of these patients. From former studies we know that most patients achieve full independence in daily activity skills[4,6]. The high number of independence at discharge of these patients in this study was not surprising. It is justified to expect that patients with paraplegia can eat, dress and make transfers independently.

For patients with tetraplegia the functional recovery of the upper extremities determines the final degree of independence. A wide variation in expectations and functional results of self-care skills was found. It means that it was difficult to agree upon the prognosis of these patients, in spite of theoretical concepts. In this study age and degree of spasticity did not differentiate between good and false predictions of self-care outcome. The role of psychosocial factors and coping was not studied, but needs attention in further studies. We assume that those factors also play an important role in the prediction and results of final outcome. As long as early prediction of self-care outcome for patients with tetraplegia is difficult, gradual adjustment of selected goals has to be taken for granted.

In Beatrixoord Rehabilitation Centre much attention is paid to the independence in self-care activities and transfers. Walking with sophisticated devices is of second importance for patients with complete lesions during the

inpatient rehabilitation period and only trained by patients with enough physical and mental indurance. The poor results regarding walking of patients with complete lesions are a logical consequence of this policy. Still, the professionals and team seemed to hesitate in being pessimistic about the future functional ambulation potential of patients with complete paraplegia. The expected and assessed results of patients with incomplete lesions (of all levels) varied widely. However, it seems clear that if the rehabilitation team and the patients agreed upon the expected independence in walking and stair climbing of patients with incomplete lesions, the results were mostly good. Again age and spasticity did not seem to play a role.

In conclusion, this study indicates the importance of assessing the expectations of both the rehabilitation team and the patient. The most reliable prediction of functional outcome after spinal cord injury was found when the expectations of both the professionals and the patients were combined. Soon after admission the prognosis of self-care was usually clear regarding patients with paraplegia, and of walking and stair climbing regarding patients with complete lesions. In this phase selection of specific goals seems reasonable. Early prediction of self-care outcome of patients with tetraplegia and mobility outcome of patients with incomplete lesions was more difficult. Gradual adjustment of rehabilitation objectives is needed during the course, in close collaboration between the individual patient and the team.

References

1. Waters RL, Adkins RH, Yakura JS, Sie I. Motor and sensory recovery following complete tetraplegia. Arch Phys Med Rehab 1993;74:242-247.
2. Waters RL, Yakura YS, Adkins RH, Sie I. Recovery following complete paraplegia. Arch Phys Med Rehab 1992;73:784-789.
3. Waters RL, Adkins RH, Yakura JS, Sie I. Motor and sensory recovery following incomplete paraplegia. Arch Phys Med Rehab 1994;75:67-72.
4. Woolsey RM. Rehabilitation outcome following spinal cord injury. Arch Neurol 1985;42:116-119.
5. Yarkony GM, Roth EJ, Heinemann AW, Wu Y, Katz RT, Lovell L. Benefits of rehabilitation for traumatic spinal cord injury. Arch Neurol 1987;44:93-96.
6. Schönherr MC, Groothoff JW, Mulder GA, Eisma WH. Functional outcome of patients with spinal cord injury. Clin Rehabil 1999;13:457-463.
7. Lazar LB, Yarkony GM, Ortolano D, Heinemann AW, Perlow E, Lovell L, Meyer P. Prediction of functional outcome by motor capability after spinal cord injury. Arch Phys Med Rehabil 1989;70:819-822.
8. Mizukami M, Kawai N, Iwasaki Y, Yamamoto Y, Yoshida Y, Koyama N, Sekiguchi S, Kimura T, Nihei R. Relationship between functional levels and movement in tetraplegic patients. A retrospective study. Paraplegia 1995;33:189-194.
9. Welch RD, Lobley SJ,O'Sullivan SB, Freed MM. Functional independence in quadriplegia: critical levels. Arch Phys Med Rehabil 1986;67:235-240.
10. Yarkony GM, Roth EJ, Heinemann AW, Lovell L. Spinal cord injury rehabilitation outcome: the impact of age. J Clin Epidemiol 1988;41:173-177.
11. DeVivo MJ, Kartus PL, Rutt RD, Stover SL, Fine PR. The influence of age at time of spinal cord injury on rehabilitation outcome. Arch Neurol 1990;47:687-691.
12. Nene AV, Hermens HJ, Zilvold G. Paraplegic locomotion: a review. Spinal Cord 1996;34:507-523.
13. Schönherr MC, Groothoff JW, Mulder GA, Eisma WH. Rehabilitation of patients with spinal cord lesions in the Netherlands: an epidemiological study. Spinal Cord 1996;34:679-683.
14. ASIA/IMSOP. Standards for Neurological and Functional Classification of Spinal Cord Injury - Revised 1992. American Spinal Injury Association, Chicago, 1992.

15. Brown PJ, Marino RJ, Herbison GJ, Ditunno JF Jr. The 72-hour examination as a predictor of recovery in motor complete quadriplegia. Arch Phys Med Rehabil 1991;72:546-548.
16. Curt A, Dietz V. Electrophysiological recordings in patients with spinal cord injury: significance for predicting outcome. Spinal Cord 1999;37:157-165.
17. Yarkony GM, Roth EJ, Heinemann AW, Lovell L, Wu Y. Functional skills after spinal cord injury rehabilitation: three-year longitudinal follow-up. Arch Phys Med Rehabil 1988;69:111-114.

Chapter 5

Vocational reintegration following spinal cord injury: expectations, participation and interventions

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Abstract

Study design: Survey
Objectives: To explore the process of reintegration in paid work following a traumatic spinal cord injury (SCI), including the role of early expectations of individual patients regarding return to work, indicators of success of job reintegration, and a description of reintegration interventions and barriers.
Setting: Dutch rehabilitation centre with special department for patients with spinal cord injuries.
Methods: Descriptive analysis of data gathered by a mailed questionnaire, which was returned by 57 persons (response 83%) with traumatic SCI, aged 18 to 60 years, and data of expectations regarding work reported by the patients during the rehabilitation admission following SCI from 1990 to 1998.
Results: Of 49 respondents who were employed at the moment of the SCI 45% expected to be able to resume work. These positive expectations were associated with a higher educational level. In 67% return to work was successful. The chance to reintegrate successfully was better if the patient expected to resume work. Logistic regression analyses did not reveal other significant indicators. About one-third of the 49 respondents working pre-injury followed vocational re-training, which was successful for most of them so far. In the majority of work situations modifications have been made, such as job adaptations and reduction of working hours. Several unmet needs regarding reintegration interventions were also reported.
Conclusions: Positive expectations regarding resumption of work after a SCI are an important indicator of successful reintegration in work. An active role of the rehabilitation team is recommended in drawing up a vocational reintegration plan to prepare the patient, the employer and all professionals involved in the reintegration process.

Introduction

Return to paid work is regarded as one of the most important outcomes of reintegration in society following a spinal cord injury (SCI)[1,2]. It gives people a social status and meaning to life and makes them more financially independent. As the majority of patients with traumatic SCI are relatively young, attention to vocational reintegration is of particular importance, not just to the patients themselves but also from a wider social point of view[3]. Job reintegration of disabled people has been an important point of political interest in The Netherlands for the last decades. However, several studies have shown that reintegration interventions do not enable all people with chronic diseases and disabilities to resume work[4-7]. The purpose of this study was to extend our knowledge about the process and the outcomes of reintegration in paid work following a spinal cord injury.

Vocational reintegration after a SCI has received considerable attention in literature. Percentages of success have varied from 25 to 48% in publications from various countries in the last decades[3,8-14]. Factors related to the success of vocational reintegration include several personal and injury-related variables, such as age, type of lesion and Barthel score, and work-related variables, such as educational level, pre-injury type of work and social security system[1-3,8-17]. Only few studies focused on the relation between vocational outcome and more subjective indicators such as work interests and values, educational and vocational plans and societal attitudes[9,14]. Nevertheless, the role of the individual patient seems very important in the process to successful job reintegration.

Research on the effects of the interventions during the vocational reintegration process following a SCI is limited[1,15,16,18]. According to Wade interventions at the level of participation include actions to maximise the behavioural repertoire of the patient and provide suitable opportunities for social interaction, such as educational and employment services[19]. Recommendations to improve vocational outcome are tailor-made educational and vocational counselling, contact with peer groups, changing employer perceptions, improving transport and equal access, and reducing financial disincentives to working[15]. Most of these proceedings take place after the rehabilitation period. Aiming at optimal participation for people with SCI we have to know which interventions promote adequate skills and strategies and create opportunities for return to work[20].

This study was conducted to gain more insight in the process of vocational reintegration, which largely takes place beyond the scope of the rehabilitation team. We were interested if early expectations of individual patients with SCI regarding return to paid work were realistic. With more knowledge of factors playing a role in the success of job reintegration prognostic information becomes available for the patient and professionals. Reintegration interventions were assessed, including vocational re-training,

job modifications and contacts with job professionals. Barriers in the process of reintegration were investigated as well.

Methods

Patients

In this study we focused on patients with an acute traumatic spinal cord injury, aged 18 to 60 years, who were consecutively admitted to the Centre for Rehabilitation Beatrixoord from 1990 until 1998. Of 89 eligible candidates 16 patients were excluded: four patients deceased, three had serious psychiatric problems, one was discharged to a nursing home, two finished their rehabilitation programme in another rehabilitation centre and six were foreigners with difficulties with the Dutch language. Of four patients the addresses were not found and they were lost for follow up. To 69 patients a questionnaire was sent. The questionnaire was filled in and returned by 57 patients, which means a response of 83%.

Questionnaire

Data on the results and process of vocational reintegration were gathered from a questionnaire, which was developed for this study. This questionnaire largely consisted of selected items of a questionnaire developed as part of the Vocational Handicap Research Programme of *TNO Arbeid* (Dutch Organisation for Applied Scientific Research). *TNO Arbeid* validated their questionnaire in several research projects[4,5]. Data became available on the employment situation both pre-injury and after the reintegration including having a job, the type of job, the job contract and number of working hours (appendix). Respondents were asked to report their income, educational level (grades 1 to 8), vocational re-training, job adjustments and contacts with reintegration professionals. The TNO assessment also includes several disease-specific items and opinions on the working conditions and social atmosphere, but these were not analysed in this study.

In order to relate the actual work situation of the respondents to the earlier expectations, the data of the predictions regarding resumption of work were used, reported by all patients during the rehabilitation period. Systematic assessment of expectations of patients with traumatic SCI was started in 1988 in the SCI department. Questions were asked such as ”Do you expect to be able to resume work (full-time or part-time)? Do you expect to be able to find a different job? Do you expect to follow vocational re-training?” Possible answers were ”yes”, ”no” and ”uncertain”. The expectations were assessed at several moments during the inpatient rehabilitation period. Data were used of the final assessment after admission.

Several personal, job-related and injury-related factors were related to the early expectations and the final success of reintegration. Data concerning work were derived from the TNO assessment. Regarding injury-related variables the type of SCI was defined according to the standards for neurological and

functional classification by the American Spinal Injury Association. The time elapsed since the injury is given in months. The ability to walk and the level of continence for urine were both assessed on a three-point scale.

Analysis

We defined successful reintegration in work as being able to return to work for at least four hours a week. Participants who returned to their jobs after the SCI and stopped working more than two years later for reasons related to the SCI, were also regarded as being successful in reintegration. Descriptive statistics were performed using the Statistical Product and Service Solutions (SPSS). Differences in the indicators between groups of patients with positive and negative expectations regarding return to their jobs, and between groups of patients with successful and unsuccessful vocational reintegration, were tested using univariate logistic regression analyses. Odds ratios were presented as they are a useful indicator of the strength of the relationship[21], and the significance level was chosen as $p < 0.05$.

Table 1. Representativeness of the response group (mean (SD) and percentages).

	Respondents $n = 57$ (83%)	*Non-respondents* $n = 12$ (17%)
Age at SCI (years): mean(SD)	33 (11)	34 (14)
Gender: Male	52 (91%)	12 (100%)
Female	5 (9%)	0 (0%)
Time since SCI (months): mean (SD)	84 (29)	99 (30)
Type of SCI: ComplTetra	6 (10%)	2 (17%)
IncompTetra	17 (30%)	4 (33%)
ComplPara	20 (35%)	5 (42%)
IncompPara	14 (25%)	1 (8%)
Job situation at SCI:		
Work	49 (86%)	5 (42%)
School	5 (9%)	4 (33%)
Other	3 (5%)	3 (25%)

Results

The study group of 57 respondents consisted of 52 males (91%) and 5 females. Their age at the moment of the SCI ranged from 18 to 59 years with a mean of 33 years. The time elapsed since injury varied from 29 to 140 months with a mean of 84 months. Forty percent of the injuries were caused by traffic accidents, 23% by industrial accidents, 37% by sports and private accidents. Six patients had complete tetraplegia, 17 patients incomplete tetraplegia, 20 patients complete paraplegia and 14 incomplete paraplegia.

The group of patients who returned the questionnaire was compared to the group who gave no response (Table 1). The most remarkable difference between the group of respondents and non-respondents is the percentage of patients that worked pre-injury. In the group of respondents 86% worked at the moment of SCI versus 42% in the group of non-responders. The time elapsed since SCI for the group of non-responders was on average longer than for the group of responders. The differences regarding age, gender and type of SCI were not significant.

Results of reintegration in paid work

At the moment of the SCI 49 of 57 respondents (86%) had a job. Five males with a mean age of 21 years went to school. Three males were out of work for a long time. Of the group of 49 respondents who were employed pre-injury 33 patients returned to work, so according to our definition successful reintegration took place in 67% of the cases. Sixteen patients (33%) failed. Of those who resumed work 20 (61%) kept working for the same employer and 9 of them changed to a different type of job. Thirteen (39%) changed to a different employer.

Successful return to a paid job took place after an interval of 3 to 108 months (median 12 months). Four of them stopped working in the mean-time after on average 67 months (range 50-90 months) after the SCI, and were not working anymore at the moment of assessment. Two persons were made redundant after a successful reintegration including vocational training, which was not related to the SCI. One is now full-time responsible for the housekeeping. Two self-employed responders initially carried on with their company after rehabilitation, but stopped after about four years working for reasons related to the SCI, namely progressive physical restrictions and mobility problems. Thirty-one percent of the 29 respondents currently working had a paid job without supplementary benefits and 69% worked with benefit from the Work Disability Act.

Early expectations and indicators of successful vocational reintegration

All patients made predictions regarding return to work during their stay in the rehabilitation centre two to ten years before the current assessment. The early expectations of the 49 respondents working pre-injury were related to their age, educational level and type of SCI, as well as to the type of job and

job contract at the moment of SCI (Table 2). A higher educational level was significantly related to positive predictions regarding return to work. All six persons with a high vocational or university education (grades 6-8) expected to return to their job.

Table 2. Comparison of groups of patients working pre-injury with positive and negative job expectations (*n*= 49) regarding personal and job-related variables and type of SCI (mean (SD) and percentages) with univariate logistic regression analyses (odds ratios (OR))

	Positive expectations *n* = 22 (45%)	*Negative expectations* *n* = 27 (55%)	OR	*p*-value
Age at SCI (years): mean (SD)	35.0 (10.9)	32.9 (9.7)	1.0	0.460
Educational level * (1-8): mean (SD)	4.8 (1.9)	3.6 (1.1)	1.7	0.012
Pre-injury contract:				0.149
- employee	11 (37%)	19 (63%)	0.4	
- self/temp-employed	11 (58%)	8 (42%)		
Pre-injury job type #:				0.165
- agr/trade/transp	14 (39%)	22 (61%)	0.4	
- adm/comm/serv/oth	8 (62%)	5 (38%)		
Type of SCI:				0.664
- compl tetraplegia	1 (20%)	4 (80%)	1.0	
- incomp tetraplegia	6 (50%)	6 (50%)	3.4	
- compl paraplegia	9 (56%)	7 (44%)	4.5	
- incomp paraplegia	6 (43%)	8 (57%)	3.0	

* $p < 0.05$
# pre-injury job type: agrarian, trade/ industrial and transport, or administrative, commercial, servicing and other scientific or technical

Table 3 shows the results of vocational reintegration of the 49 patients with a job pre-injury related to the early expectations. Of the 22 patients who expected to be able to resume work, 20 respondents (91%) succeeded to return to work, of which nine actually returned to the same job. Of two (9%) the job reintegration failed. Of the 23 patients who expected not to be able to return to their job, but to be able to find a different job or study, 11 respondents (48%) reintegrated successfully. One returned to his own job and 10 found a different job. Twelve persons in this group (52%) failed to

return to work. Of the four patients with a job pre-injury who did not expect to be able to return to work or follow a study, two returned to work and two did not. The chance to reintegrate successfully was much better if the patient expected to be able to resume work with an odds ratio of 10.8 (95% confidence interval 2.1 - 55.4).
Of the five students four expected to return to their study and one expected to be able to follow a different study. They all found a job. Of the three respondents who were out of work for a long time before SCI all had negative expectations and they remained unemployed.

Table 3. Expectations regarding return to work of patients with work pre-injury (*n*=49) related to the results of job reintegration (n (%)).

	Reinte-gration successf	*Same employer same job*	*Same employer other job*	*Other employer*	*Reinte-gration failed*	*Total*
Expects to be able to return to job	**20**	9	5	6	**2**	**22** (45%)
Expects not to return, but to find other job or study	**11**	1	3	7	**12**	**23** (47%)
Expects not to return to work or study	**2**	1	1	0	**2**	**4** (8%)
Total	**33** (67%)	11	9	13	**16** (33%)	**49** (100%)

In Table 4 we show the correlation of the success of vocational reintegration with several personal, injury-related and work-related factors and did not find any other significant relations than the early expectations. Regarding the level of education 59% of the lower educated patients reintegrated successfully compared to 69% of the patients with an intermediate educational level and 100% of the higher educated persons.

Table 4. Comparison of groups of patients with successful and unsuccessful reintegration in work (*n*=49) regarding personal, job-related and SCI-related variables and job expectations (mean (SD) and percentages) with univariate logistic regression analyses (odds ratios (OR)).

	Reintegration succeeded *n*= 33 (67%)	*Reintegration failed* *n* = 16 (33%)	OR	*p*-value
Personal factors				
Age at SCI (years): mean (SD)	33.9 (10.3)	33.7 (10.8)	1.0	0.950
Educational level (1-8): mean (SD)	4.4 (1.7)	3.6 (1.2)	1.5	0.087
SCI-specific factors				
Type of SCI:				0.336
- compl tetraplegia	2 (40%)	3 (60%)	1.0	
- incompl tetraplegia	10 (77%)	3 (23%)	5.0	
- compl paraplegia	10 (59%)	7 (41%)	2.1	
- incompl paraplegia	11 (79%)	3 (21%)	5.5	
Remain dry:				0.921
- yes	16 (67%)	8 (33%)	0.9	
- no/ with difficulty	17 (68%)	8 (32%)		
Walking:				0.090
- yes/ with difficulty	19 (79%)	5 (21%)	3.0	
- no	14 (56%)	11 (44%)		
Work-related factors				
Pre-injury job type #:				0.137
- agr/trade/transp	22 (61%)	14 (39%)	0.3	
- adm/comm/serv/oth	11 (85%)	2 (15%)		
Pre-injury job contract:				0.453
- employed	19 (63%)	11 (37%)	0.6	
- self/temp-employed	14 (74%)	5 (26%)		
Vocational re-training:				0.429
- yes	12 (75%)	4 (25%)	1.7	
- no	26 (68%)	12 (32%)		
Job expectations *:				0.004
- positive	20 (91%)	2 (9%)	10.8	
- negative	13 (48%)	14 (52%)		

* $p < 0.05$

pre-injury job type: agrarian, trade/ industrial and transport, or administrative, commercial, servicing and other scientific or technical

Vocational reintegration interventions

Of 49 patients who were employed pre-injury 16 respondents (33%) reported participation in vocational re-training. All but one were below 40 years of age. Of 22 persons with intermediate and high levels of education 11 (50%) followed vocational re-training *versus* five (19%) of 27 persons with a lower level of education. The training group contained relatively more patients with a complete tetraplegia and more employees. Four of 16 (with secondary vocational education) failed to return to work so far. Three of them did a successful work placement as part of vocational re-training, but were not able resume work yet and hoped to find a job within a few months. Thirteen (81%) of them were satisfied with the vocational re-training. Three respondents reported they missed vocational re-training.

In 23 of the 29 current work situations (79%) job modifications have been made. It concerned material adaptations such as personal aids (38%) and adapted furniture or toilet facilities (45%). Adequate transport was arranged for 24% of the workers. Regarding immaterial modifications 52% of the workers got the opportunity to work with personal time management (planning your own working day), 38% with flexible working hours, and 31% with less tasks. Eighteen persons (62%) lost working hours in comparison with the situation before the SCI: five reported a reduction of 75-90%, ten a reduction of 25-74% and three reduced their working hours to less than 25%. At the moment of the SCI they worked on average 48.7 hours a week, while present job hours averaged 29.3 hours a week. Employees worked on average 44.6 hours pre-injury *versus* 30.1 hours a week now. Self-employed workers worked 60.0 hours pre-injury *versus* 27.9 hours a week now.

The 29 respondents who still worked at the moment of assessment also reported unmet needs regarding the reintegration process. Seven (21%) of the present workers wished (more) job modifications, especially more personal time management, the opportunity to work at home, or (more) adaptations at the workplace. Six (18%) wished more contacts with reintegration professionals.

Unsuccessful job reintegration

Regarding our definition of successful reintegration 16 patients failed to return to work and mentioned the SCI as a reason for not working. Problems related to the SCI were described as physical limitations by 88% of the respondents, and fatigue and mental problems by 25%. Environmental problems were mobility and transport problems (63%), lack of sanitary supplies (31%), and lack of adjusted work or specific adaptations (38%). All 16 were entitled to benefit from the Work Disability Act.

Of these 16 persons three (19%) mentioned that they missed vocational re-training. Five persons (31%) responded that they might have been working now if job modifications had been made. It concerned both material and immaterial adaptations. Six respondents (38%) preferred more contacts

with professionals, particularly with professionals responsible for the execution of the Work Disability Act, but also the physician of occupational health (company doctor) and professionals of the rehabilitation centre.

Eleven persons who failed so far (69%), still wished to return to work under certain conditions that take a good health, adequate job modifications, education and financial situation into account. Four were optimistic regarding their reintegration and expected to get a job within a few months or one year. Three of them followed vocational re-training recently. The other 12 respondents were less optimistic: three did not know when they might return to work and six did not expect to find a job again. Comparison of the unmet needs of the two subgroups who succeeded or failed to return to work is presented in Table 5 .

Table 5. Results of job reintegration at the moment of assessment (*n*=45) related to the unmet needs regarding the process of reintegration and application for a (different) job (*n*(%)).

	n	*Missed training*	*Wish for (more) modifi-cations*	*Wish for (more) counsel-ling*	*Apply for job*
Currently working	29	0 (0%)	7 (21%)	6 (18%)	2 (6%)
Reintegration failed	16	3 (19%)	5 (31%)	6 (38%)	4 (25%)

Discussion

Return to work is regarded as one of the most important long-term rehabilitation goal[1,2]. Despite the serious consequences of the SCI regarding ambulation, functional independence and social continence, this should never be a reason to exclude SCI disabled people from the labour market without exploring vocational possibilities. People with SCI have a basic right to work[6]. The principle findings in this study were that the rate of successful job reintegration was higher than expected from literature and that the expectations of the individual patient regarding future participation after a SCI are an important indicator of the vocational outcome. Apart from successful participation in vocational re-training and a large number of job modifications which facilitated the reintegration in work, also several unmet needs were reported by respondents who succeeded as well as by those who failed.

The process of vocational reintegration was explored in a retrospective study. Bias was negligible as we included all patients with traumatic SCI that were admitted to the rehabilitation centre in the given period and gathered a

representative response group. Because of small numbers we included all types of SCI. As almost all patients with SCI in the age group until 60 years in The Netherlands are admitted to rehabilitation centres, the results can be generalised to the whole Dutch SCI population with vocational potential. The interval between the injury and the current assessment showed a lot of variation. The SCI existed at least two years taking the moment of the definitive assessment of the disablement according to the Dutch Work Disability Act into account.

The Dutch legislation regarding work disability is complex and different from that of most other countries. Because of a large number of work disabled people in The Netherlands several changes in legislation have been made in the last decade, aiming at the increase of reintegration in work. In the first year of absence from work due to illness or injury, the employee receives full compensation of salary based on the principles of the Sickness Benefit Act. Both the employer and the employee are responsible for prevention of sick leave and reintegration in work. Self-employed persons usually are insured to compensate their loss of income. From the second year of absenteeism disabled workers are entitled to benefit from the Work Dependent Act dependent on the loss of earning capacity regarding employment which can be managed. The employer is still obliged to support resumption of work or to offer an alternative job. At the end of this second year a decision of disablement can take place, either leading to continuation of employment with or without benefits from the Work Disability Act, or to termination of the employment. Supplementary benefits from the Work Disability Act and an employer's bonus for the number of disabled in the company should make it more attractive for employers to keep disabled people employed. In spite of this, chronically disabled persons experience many problems and are often insufficiently enabled to reintegrate in the employment process[4-7].

The percentage of 67% who reintegrated successfully in the present study was higher than expected. American studies in the eighties showed poor rates up to a maximum of 25% of persons being employed after the SCI[8-11]. In more recent American, Australian and European studies the percentages of persons gainfully working at assessment improved and ranged from 31 to 48%[3,12-15]. Success rates are determined by the social security system, economic circumstances and the willingness of employers to keep disabled people at work[22]. The booming economy of the last decade and the labour shortage due to ageing of the labour potential was in favour of those with chronic diseases and disabilities. The variation in study samples in terms of demographic and injury-related characteristics makes it difficult to compare results of different studies. In a Dutch multi-centre study Tomassen *et al.* reported that 37% of pre-injury workers were gainfully employed after the SCI[16]. An explanation for our higher success rate is not easily given. Factors such as socio-economic and cultural circumstances were not analysed in this study.

Significant objective indicators for successful reintegration in work were not identified in this study group. Predictors of successful job reintegration were subject of extensive research on vocational outcome of people with SCI. Returning to work is a complex process that results from an interaction of impairment and personal and environmental factors[18]. Most studies focused on demographic and injury-related factors[1-3,8-15]. Work-related and environmental factors were studied such as pre-injury employment status, vocational re-training, transportation and architectural barriers[1-4,9-13,15,17]. A predictive model for vocational outcome was developed in one study, in order to increase the cost-effectiveness of vocational rehabilitation by focusing efforts on the individuals with the greatest vocational potential[11].

It is a noteworthy finding that the vocational outcome of patients who expected to be able to return to work was significantly better than of patients who did not, even if they expected to be able to find another job or study. As far as we know the role of early expectations of the individual patient regarding work was scarcely studied in relation to vocational outcome[9,14]. Lack of realistic vocational expectations was associated with lower work rates[9]. Wade assumed that the results of rehabilitation interventions depend on the goals a patient wishes to attain, which are determined by the future state that is desired and expected[23]. Positive expectations of our study group regarding work were associated with a higher educational level. Identification of subjective factors, such as work values, coping abilities, motivation, but also social contacts at the work place, credits of the employer, and financial disincentives (losing benefits when becoming gainfully employed), should be subject of further research. We concluded that positive expectations of the patient are a complex but strong indicator of successful reintegration. Individual coaching of the group with less optimistic expectations should start during the rehabilitation period. Focus on adequate coping abilities, motivation to work, and willingness of the employer, can reduce the risk of losing jobs.

In The Netherlands individual job counselling and vocational services are formally available for all disabled persons. Studies on the effects of reintegration interventions for SCI disabled are scarce[1,15,16,18] and need attention. In this study one-third of pre-injury working respondents followed vocational re-training, which is comparable with other studies[12,13]. The majority of them reintegrated successfully. Vocational re-training can open up job possibilities which are less physically demanding, such as desk work and computer. However, especially for persons with lower levels of education these jobs are not always attractive and pay less, so persons experience less incentive to return to work[15,16]. More information about the contents and additional value of vocational re-training is needed to stimulate patients and professionals to make use of these programmes.

Job modifications are often indispensable to reintegrate successfully in former and new jobs. Reduction of time pressure, flexible work schedules, barrier free access and transportation, ergonomic work station design, and

positive attitudes of employer and fellow employees, were recommended in literature[4,5,18,24]. In this study two-thirds of persons at work underwent substantial changes in working hours. Employees reduced their average working hours to two-thirds and self-employed workers even to half of their former working hours. Financial consequences were usually at least partially compensated by benefit from the Work Disability Act, which makes it attractive to carry on working. In spite of all the adaptations already carried out, the need for supplementary adjustments and more contacts with professionals should not be neglected.

All patients who failed to resume work, related this to problems due to the SCI, particularly physical restrictions. A substantial part of them wished more support from professionals (38%) and might have returned to work, if more job modifications had been made. Mobility and transport problems, as well as lack of specific adaptations at the workplace, are still reported too often and seem unnecessary. We assume that more individual attention to the unmet needs of those people might have given better results of employment. At the beginning of the reintegration process the majority of these patients expected to be able to find another job or re-training. Although most of them still wished to return to work, they lowered their expectations, which illustrates the adjustment to a situation without paid work.

To avoid disappointment and poor results of reintegration we advocate that focus on vocational reintegration should start before discharge from the rehabilitation centre. The rehabilitation team can play an active role in drawing up a reintegration plan, supported by the patient and employer. Insight in the expectations of the patient improves the prognostic information regarding return to work and should be an essential part of the assessment. An inventory is recommended of the feasibility of return to the job, educational opportunities and required job modifications. A case manager who links the patient, the employer, the rehabilitation team and other professionals involved in the reintegration process, can play an important role. With up-to-date information and coaching through the forest of rules and legislation, the patient keeps closely associated with the complex process of vocational reintegration.

In-depth interviews are needed to gain more insight in the process leading to job reintegration following a SCI, to enhance the quality of individual counselling and effective interventions. Effect studies on the result of vocational reintegration programmes are an important next step.

Conclusions

Early positive expectations of the individual person with a SCI are an important indicator of successful reintegration. Assessment of these expectations can improve prognostic information regarding resumption of work and enhance vocational rehabilitation programmes. The rehabilitation team can play an active role in drawing up a vocational reintegration plan to

prepare the patient, employer and all professionals involved for job reintegration.

References

1. Krause JS. Employment after spinal cord injury. Arch Phys Med Rehabil 1992;73:163-169.
2. Noreau L, Dion S-A, Vachon J, Gervais M, Laramée M-T. Productivity outcomes of individuals with spinal cord. Spinal Cord 1999;37: 730-736.
3. Taricco M, *et al*. The social and vocational outcome of spinal cord injury patients. Paraplegia 1992;30:214-219.
4. Andries F, *et al*. Vocational perspectives and neuromuscular disorders. International Journal of Rehabilitation Research 1997;20:255-273.
5. Wevers CWJ, Brouwer OF, Padberg GW, Nijboer ID. Job perspectives in facioscapulohumeral muscular dystrophy. Disability and Rehabilitation 1993;15:24-28.
6. Groothoff JW. Reïntegratie: ga terug naar af (official speech of inauguration). University of Groningen, 2002.
7. Hoekstra EJ. Arbeidsbemiddeling met behulp van Supported Employment als interventie bij de reïntegratie van chronisch zieken (thesis). Groningen: University of Groningen, 2002
8. Woolsey RM. Rehabilitation outcome following spinal cord injury. Arch Neur 1985;42:116-119.
9. Goldberg RT, Freed MM. Vocational development of spinal cord injury patients: an 8-year follow-up. Arch Phys Med Rehabil 1982;63:207-210.
10. DeJong G, Branch LG, Corcoran PJ. Independent living outcomes in spinal cord injury: multivariate analyses. Arch Phys Med Rehabil 1984;65:66-73.
11. DeVivo MJ, Rutt RD, Stover SL, Fine PR. Employment after spinal cord injury. Arch Phys Med Rehabil 1987;68:494-498.
12. Murphy G, Brown D, Athanasou J, Foreman P, Young A. Labour force participation and employment among a sample of Australian patients with spinal cord injury. Spinal cord 1997;35:238-244.
13. Siösteen A, Lundqvist C, Blomstrand C, Sullivan L, Sullivan M. The quality of life of three functional spinal cord injury subgroups in a Swedish community. Paraplegia 1990;28:476-488.
14. Berghammer A, Gramm M, Vogler L, Schmitt-Dannert H-H. Investigation of the social status of paraplegic individuals after medical rehabilitation. Spinal cord 1997;35:493-497.
15. Conroy L, McKenna K. Vocational outcome following spinal cord injury. Spinal Cord 1999;37:624-633.
16. Tomassen PCD, Post MWM, Asbeck FWA van. Return to work after spinal cord injury. Spinal Cord 2000; 38:51-55.
17. Levi R, Hultling C, Seiger A. The Stockholm spinal cord injury study: 4. Psycho-social and financial issues of the Swedish annual

level-of-living survey in SCI subjects and controls. Paraplegia 1996;34:152-157.
18. Pentland W, Harvey AS, Smith T, Walker J. The impact of spinal cord injury on men's time use. Spinal Cord 1999;37:786-792.
19. Wade DT. A framework for considering rehabilitation interventions. Clin Rehabil 1998;12:363-368.
20. Cushman LA. Spinal cord injury: 10 and 15 years after. Paraplegia 1992;30:690-696.
21. Bland JM, Altman DG. Statistics Notes: The odds ratio. BMJ 2000;320:1468 (http://bmj.com/cgi/reprintsidebar/320/7247/1468??eaf)
22. Post MWM, Witte LP de, Asbeck FWA van, Dijk AJ van, Schrijvers AJP. Predictors of health status and life satisfaction in spinal cord injury. Arch Phys Med Rehabil 1998;78:395-402.
23. Wade DT. Evidence relating to goal planning in rehabilitation. Clin Rehabil 1998;12:273-275.
24. Schoppen T, Boonstra AM, Groothoff JW, Vries J de. Göeken, LNH, Eisma WH. Employment status, job characteristics and work related health experience of people with lower limb amputation in the Netherlands. Arch Phys Med Rehabil 2001;82:239-245.

Appendix

Questionnaire for workers as part of the Vocational Handicap Research Programme of *TNO Arbeid* (items not used in this study are in italics):

1. *Disease-specific items*
2. *Health: assessment of health perception on 9 dimensions (RAND 36)*
3. Income
4. Educational level
5. Pre-injury employment situation:
   - Type of job: agrarian, trade/ industrial, transport, administrative, commercial, servicing, other scientific or technical
   - Job contract: permanent employed, temporary employed, self-employed, other
   - Working hours
6. Current employment situation:
   - Type of job: agrarian, trade/ industrial, transport, administrative, commercial, servicing, other scientific or technical
   - Job contract: permanent employed, temporary employed, self-employed, other
   - Working hours
7. Job modifications:
   - Change of job or employer
   - Material and immaterial adaptations of the job
   - Wish for (more) job modifications
   - Wish for (more) contacts with reintegration professionals
8. *Opinions about the current working conditions and social atmosphere*
9. Situation of those who stopped working:
   - Reasons for not working
   - Wish for job modifications
   - Wish for (more) contacts with reintegration professionals
   - Expectations regarding return to work

Chapter 6

Vocational outcome after spinal cord injury: experiences, satisfaction and unmet needs

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Submitted

Abstract

Study design: Survey
Objectives: To give insight in the vocational situation several years after a traumatic spinal cord injury (SCI), including the relation with the health status and work-related disabilities, and to give a description of the personal experiences and satisfaction with the current job situation.
Setting: Dutch rehabilitation centre with special department for patients with spinal cord injuries.
Methods: Descriptive analysis of data gathered by a mailed questionnaire, which was returned by 57 individuals (response 83%) with a traumatic SCI, aged 18 to 60 years, admitted to the rehabilitation centre from 1990 to 1998.
Results: An overview is given of the health status, disabilities and satisfaction per type of SCI. The number of work-related disabilities and perceived physical functioning were associated with the extent of the lesion and not with the level of the lesion. There were no differences between the subgroups with different types of SCI as far as being employed or general satisfaction were concerned. At the moment of assessment 60% of the respondents had a paid job which was related to a higher educational level. The respondents who changed to a different employer needed more time to resume work, but seemed more satisfied with the job and lost fewer working hours than those who resumed work at the former employer. In spite of a reasonable to good satisfaction with the current work situation, several negative experiences and unmet needs were reported.
Conclusions: Vocational outcome after a SCI is not associated with SCI-specific factors. As the educational level is an important indicator, educational opportunities for people with SCI should be stimulated. Personal experiences of working people with SCI should not be neglected and regular follow-up of the rehabilitation team is advocated, including attention paid to the job situation.

Introduction

Quality of life after a spinal cord injury (SCI) depends on the way a patient learns to adapt to the fundamental changes in his life and the reintegration into society. Active involvement in activities seems strongly related to health and well-being[1,2]. Participation includes reintegration in work and school, but also significant involvement in housekeeping and community organisations[3]. From a social point of view return to work is regarded as one of the most important outcomes of reintegration in society[4,5]. From other studies we know that the chances to resume work are restricted for patients with chronic diseases and disabilities[2,6,7]. The aim of this study was to give insight in the vocational situation of SCI disabled in The Netherlands, several years after the SCI.

Several studies reported quantitative results of employment status after a SCI and work rates vary from 31 to 48%[8-11]. In a Dutch multi-centre study 37% of pre-injury workers were gainfully employed after the SCI[12]. Several authors identified factors related to return to work[4,5,8-17]. Predictors of vocational outcome often mentioned in literature are age, education level, motivation, pre-injury type of job, and disease-specific problems and disabilities. Several subjective factors such as motivation and expectations of the patient regarding return to work will affect the outcome to a great extent[10,13].

The Dutch Organisation for Applied Scientific Research (*TNO Arbeid*) has developed a research programme to evaluate the vocational situation of people with chronic diseases. The main goal of this Vocational Handicap Research Programme was to describe the working conditions and reintegration experiences of chronic disabled with various diagnoses, to create a more positive image of their capabilities and improve reintegration interventions[2,6]. The studies of *TNO Arbeid* highlight the aspects of work of people with various diagnoses. Persons with SCI have not been under study yet.

Post *et al.* performed a nation-wide study on the health status and life-satisfaction of Dutch people with a SCI, which revealed relationships between rehabilitation outcomes of different dimensions[18]. Little is known about the role of SCI-specific factors in vocational outcome. Satisfaction with the vocational situation after a SCI is usually low, which can be explained by change to unrewarding, poor-quality jobs and insufficient income[19,20]. We assumed that the satisfaction with several aspects of work during and after resumption of work determines if the disabled worker will keep his job or not.

With more knowledge about specific problems due to the SCI that affect the job situation, the rehabilitation team can prepare patients and family and teach them how to cope with these matters. Information about unmet needs after the reintegration can help job professionals to keep people with SCI at work. In this study several aspects of vocational outcome were analysed of

people with SCI, who were currently working after a successful reintegration. We assessed the current health status, disabilities and dependence on help related to work. Several changes regarding the job situation were studied, including changes in working hours, job adjustments and contacts with professionals. We gathered the personal experiences, job satisfaction and unmet needs in the current work situation.

Methods

Patients

In this study we focused on patients with acute traumatic spinal cord injury, aged 18 to 60 years, who were consecutively admitted to the Centre for Rehabilitation Beatrixoord from1990 to 1998. Of 89 eligible candidates 16 patients were excluded: four patients deceased, three had serious psychiatric problems, one was discharged to a nursing home, two finished their rehabilitation programme in another rehabilitation centre and six were foreigners with difficulties with the Dutch language. Of four patients the addresses were not found and they were lost for follow up. To 69 patients a questionnaire was sent. The questionnaire was filled in and returned by 57 patients, which means a response of 83%.

Questionnaire

Data on the current vocational situation and several factors that might be associated with this outcome were gathered from a questionnaire, which was developed for this study. This questionnaire largely consisted of selected items of a questionnaire developed as part of the Vocational Handicap Research Programme of *TNO Arbeid* (Dutch Organisation for Applied Scientific Research). *TNO Arbeid* validated their questionnaire in several research projects[2,6]. Data became available on the employment situation of this study group both pre-injury and after the reintegration. Respondents were asked to report their income, educational level (grades 1-8), vocational re-training, changes in job or employer, changes in working hours, adaptations of the workplace, contacts with professionals, and their opinion on the working conditions and social atmosphere. Satisfaction with the job ranged from not satisfied to satisfied (grades 1 to 4). The TNO assessment also includes several injury-related scales regarding work-related disabilities (TNO score 0-54) and dependence on help (TNO weighted score 0-42) (appendix).

The type of SCI was defined according to the standards for neurological and functional classification by the American Spinal Injury Association. The study group was divided into four subgroups: (1) complete tetraplegia; (2) incomplete paraplegia; (3) complete paraplegia; (4) incomplete paraplegia.We used a validated scale with eight health problems related to SCI experienced in the last four weeks before assessment[18]: respiratory problems, pain, spasms, contractures, excessive sweating, oedema, pressure sores, urinary tract

infections (score 0-8). We asked an estimation of the time in minutes used for self-care pre- and post-injury and calculated the extra time currently needed. The ability to walk and the level of continence for urine were both assessed on a three-point scale.

The impact of the health status was assessed by the RAND 36 (Dutch version)[21]. The RAND 36 is a short version of the RAND Health Insurance Study Questionnaire and is similar to the MOS SF-36. It measures health perception on nine multi-item dimensions: physical functioning, social functioning, physical role restriction, emotional role restriction, mental health, vitality, pain, general health and health change. A lower score is indicative of a worse health experience.

For information on life satisfaction we used the Fugl-Meijer Life Satisfaction Questionnaire (LSQ)[22]. The questionnaire was translated in Dutch and validated by Post *et al* [20]. The LSQ measures general life satisfaction and satisfaction on eight life domains, including satisfaction with self-care ability, the leisure situation, the vocational situation, the financial situation, sexual life, partnership relation, family life and contacts with friends. LSQ item scores range from grade 1 (very dissatisfying) to grade 6 (very satisfying).

Analysis

We defined having paid work as being able to work gainfully for at least eight hours a week. Descriptive statistics were performed using the Statistical Product and Service Solutions (SPSS). Analyses of variance and multiple comparisons of the groups were used to compare the subgroups with different types of SCI regarding health status, disabilities and satisfaction. Differences in the indicators between groups of patients with and without a paid job were tested using univariate logistic regression analyses. Odds ratios were presented as they are a useful indicator of the strength of the relationship[23], and the significance level was chosen as $p < 0.05$.

Results

The study group of 57 respondents consisted of 52 males (91%) and 5 females. Their age at the moment of the SCI ranged from 18 to 59 years with a mean of 33 years. The time since injury varied from 29 to 140 months with a mean of 84 months. Forty percent of the injuries were caused by traffic accidents, 23% by industrial accidents, 37% by sports and private accidents. Six patients had complete tetraplegia, 17 patients incomplete tetraplegia, 20 patients complete paraplegia and 14 incomplete paraplegia.

The group of patients who returned the questionnaire was compared to the group who gave no response (Table 1). The most remarkable difference between the group of respondents and non-respondents is the percentage of patients who worked at the moment of the SCI. In the group of respondents 86% worked pre-injury versus 42% in the group of non-responders. The time

elapsed since the SCI was on average longer for the group of non-responders than for the group of responders. The differences regarding age, gender and type of SCI were not significant.

Table 1. Representativeness of the response group (mean (SD) and percentages).

	Respondents *n* = 57 (83%)	*Non-respondents* *n* = 12 (17%)
Age at SCI (years): mean(SD)	33 (11)	34 (14)
Gender: Male (%)	52 (91%)	12 (100%)
Female (%)	5 (9%)	0 (0%)
Time since SCI (months): mean (SD)	84 (29)	99 (30)
Type of SCI: ComplTetra (%)	6 (10%)	2 (17%)
IncompTetra (%)	17 (30%)	4 (33%)
ComplPara (%)	20 (35%)	5 (42%)
IncompPara (%)	14 (25%)	1 (8%)
Job situation at SCI:		
Work (%)	49 (86%)	5 (42%)
School (%)	5 (9%)	4 (33%)
Other (%)	3 (5%)	3 (25%)

Health status and work-related disabilities

Several aspects of the health status, the work-related disabilities and dependence on help were analysed in the four subgroups with different types of SCI, and the results are shown in Tables 2a and 2b. Health problems were experienced by 83% of the 57 respondents in the last four weeks before the assessment with a mean of two problems per individual. More than half of the study population reported pain (56%) and spasms (61%). Pain and spasms were not significantly related to the type of SCI. Oedema (23%), urinary infections (21%), excessive sweating (18%) and pressure sores (9%) were reported less frequently. Most of the respondents with incomplete lesions were able to walk with or without difficulty and all persons with complete lesions were fully wheelchair-bound. About one-quarter of the people with tetraplegic lesions had problems with continence for urine, versus two-thirds of the persons with paraplegic lesions.

The analyses of variance showed differences between the subgroups regarding work-related disabilities, dependence on help, extra time for self-

care, satisfaction with self-care abilities (LSQ) and perceived physical functioning (RAND36). None of the other dimensions of health experience (RAND36) and domains of life satisfaction (LSQ) were related to the level and extent of the lesion. Multiple comparison of the groups showed that persons with complete tetraplegia needed significantly more help with self-care, and also with transport and domestic activities, and were least satisfied with their self-care abilities. Complete lesions were associated with a significantly higher number of work-related disabilities, more extra time for self-care and lower perceived physical functioning in the RAND36.

Table 2a. Comparison of subgroups with different types of SCI (*n*= 57) regarding health problems, walking, continence for urine, dependence on help and having a paid job (%).

	Complete Tetra *n* = 6	*Incomplete Tetra* *n* = 17	*Complete Para* *n* = 20	*Incomplete Para* *n* = 14	*Total* *n* = 57
Pain	83%	41%	60%	57%	32 (56%)
Spasms	67%	71%	65%	43%	35 (61%)
Walking:					
-Yes	0%	29%	0%	7%	6 (10%)
-With diff		65%		79%	22 (39%)
-No	100%	6%	100%	14%	28 (51%)
Continent:					
-Yes	67%	76%	30%	43%	29 (51%)
-With diff	16%	18%	35%	36%	16 (28%)
-No	16%	6%	35%	21%	12 (21%)
Help with self-care	100%	6%	11%	0%	9 (16%)
Help with transport	67%	24%	25%	14%	14 (25%)
Paid work	50%	53%	60%	71%	34 (60%)

Vocational outcome

Of 57 respondents 49 patients (86%) had a job at the moment of the SCI. Five males with a mean age of 21 years went to school. Three males were out of work for a long time. Of the group of 49 respondents who were employed pre-injury 33 patients returned to work and 16 patients failed. Return to a paid job took place after an interval of 3 to 108 months (median 12 months). Four of them stopped working in the meantime after on average 67 months (range 50-90 months) after the SCI and were not working anymore at the moment of assessment. Two persons were made redundant after a successful reintegration including vocational training, not related to the SCI. One is now full-time responsible for the housekeeping. Two self-employed responders initially carried on with their company after rehabilitation, but stopped after about four years working for reasons related to the SCI, like progressive physical restrictions and mobility problems.

Table 2b. Comparison of subgroups with different types of SCI (n = 57) regarding health status, disabilities and aspects of self-care (mean (SD)) using analyses of variance.

	Complete Tetra n = 6	*Incomplete Tetra* n = 17	*Complete Para* n = 20	*Incomplete Para* n = 14	*Total* n = 57
Health probl (0-8)	2.5 (1.5)	1.7 (1.3)	2.4 (1.46)	1.5 (1.2)	2.0 (1.4)
Disabilities* (0-54)	26.7 (2.8)	13.5 (4.5)	22.9 (2.7)	13.9 (4.7)	18.3 (6.4)
Dependence* (0-42)	33.0 (11.2)	7.1 (10.4)	10.0 (9.0)	2.9 (4.1)	9.8 (12.1)
Extra time * for self-care	68.3 (22.3)	19.7 (41.3)	60.0 (41.1)	28.9 (31.3)	40.9 (41.3)
Perc. phys.* funct (0-100)	10.0 (13.4)	45.6 (27.2)	17.1 (10.6)	46.1 (24.0)	32.2 (25.3)
Satisfaction* self-care(1-6)	2.0 (1.1)	4.6 (1.5)	4.7 (0.8)	4.8 (1.0)	4.4 (1.4)
Satisfaction general (1-6)	4.2 (1.2)	4.4 (1.2)	5.0 (0.8)	4.5 (1.0)	4.6 (1.0)

* p<0.05

At the moment of assessment 34 persons (60%) had paid work, including 29 pre-injury workers and 5 students who graduated in the meantime. It concerned 50% of persons with complete tetraplegia, 53% of persons with incomplete tetraplegia, 60% of persons with complete paraplegia and 71% of persons with incomplete paraplegia. Table 3 shows that a higher educational level is a significant indicator of being employed after a SCI. Neither age, health problems, work-related disabilities nor the dimensions of health experience (RAND36) and life satisfaction (LSQ) were significantly related to the current work situation.

Table 3. Comparison of subgroups with or without a paid job regarding personal and SCI-related variables and satisfaction (mean (SD)) using univariate logistic regression analyses (odds ratios (OR)).

	Paid job *n*= 34 (60%)	*No paid job* *n* = 23 (40%)	OR	*p*-value
Age now (yrs)	38.4 (9.4)	42.8 (11.9)	1.0	0.122
Educational level * (1-8)	4.7 (1.8)	3.5 (1.4)	1.6	0.019
Time since SCI (mths)	89.4 (31.5)	76.7 (24.2)	1.0	0.109
Health problems (0-8)	2.2 (1.3)	1.7 (1.5)	1.3	0.256
Disabilities (0-54)	15.8 (7.1)	17.3 (5.2)	1.0	0.369
Dependence (0-42)	8.1 (9.9)	12.4 (14.6)	1.0	0.197
Extra time self-care (min)	36.1 (35.6)	47.8 (48.4)	1.0	0.297
Perceived phys func(0-100)	37.0 (28.4)	25.4 (18.6)	1.0	0.099
Satisfaction self-care (1-6)	4.6 (1.2)	4.1 (1.6)	1.3	0.246
Satisfaction general (1-6)	4.6 (1.1)	4.6 (0.9)	1.0	0.832

* $p < 0.05$

Job modifications

Of the 29 respondents working pre-injury eight (28%) were able to reintegrate in the same job. Nine changed to a different job at the same employer (31%) and twelve (41%) found a new job at a different employer. At the moment of the SCI the persons with a paid job worked on average 48.7 hours a week, while present job hours averaged 29.3 hours a week

(range 4 to 70 hours). Eighteen persons (62%) worked less hours than before the SCI: five reported a reduction of 75-90%, ten a reduction of 25-74% and three reduced their working hours to less than 25%. Thirteen of the 34 working respondents (38%) had a paid job without any supplementary benefit and 62% worked with benefit from the Work Disability Act.

In 25 of the 34 present work situations (74%) job adjustments had been made. The majority of respondents (80%) received one or more material job adaptations such as personal aids (38%) and adapted furniture or toilet facilities (44%). Adapted transport was available for 24% of the workers. Nine percent received help with self-care. Immaterial adjustments were arranged for 88% of the workers. Personal time management (planning your own working day) was mentioned by 50% of the workers, and they also reported flexible working hours, less tasks and a slower work tempo. One-quarter were able to work at home.

Table 4. Changes to a different job or employer of respondents currently working (*n*=34) related to reintegration aspects and current experiences.

	Same employer, same job *n*=8	*Same employer, other job* *n*=9	*Other employer* *n*=12	*No job pre-injury* *n*=5	*Total* *n*=34
Reintegration aspects:					
-Months not working: median (range)	9 (3-12)	9 (6-18)	20 (8-108)	-	12 (3-108)
-Vocational re-training: %	13%	22%	58%	-	34%
-Change job hours: %	63%	89%	42%	-	62%
-Adaptation of workplace: %	75%	89%	75%	40%	74%
Current experiences:					
-Benefit from WDA: %	63%	100%	50%	20%	62%
-Contacts with professionals: %	63%	67%	33%	40%	50%
-Wish (more) adaptations: %	25%	44%	8%	0%	21%
-Good job satisfaction: %	75%	44%	75%	60%	65%

In Table 4 we related the changes to a different job or employer to several aspects of the job reintegration. Respondents who changed to a different job at the same employer (31%) experienced the most changes in working hours (89%) and job adjustments (89%). They were all working with full or partial benefit from the Work Disability Act (WDA). The majority of those who changed to a different employer (41%) followed vocational re-training (58%) and needed the longest time to return to work. This subgroup showed the least change of working hours, the least benefits from the WDA, the least current contacts with work professionals, and the least need for more adaptations. The majority of them were satisfied with the job.

Job satisfaction, personal experiences and unmet needs

The assessment of satisfaction with the job on the TNO questionnaire showed that one person (3%) was "not satisfied" (grade 1), one person (3%) was "little satisfied", ten persons (29%) were "reasonably satisfied" (grade 3) and 22 persons (65%) were "satisfied" with their jobs (grade 4). According to the results of the Life Satisfaction Questionnaire this group showed a median score of 5 (satisfying) regarding their vocational situation and for life as a whole.

Regarding the experiences in the present work situation 43% of workers reported physical strain, 68% reported mental strain and 46% were working under time pressure. A quarter found their work tiring, 36% mentioned they should calm down in their work and 16% that their health was influenced negatively by their work. Most of these workers judged the accessibility positively (88%) and none of them had transport problems. In 44% of the work situations the respondents were dependent on their colleagues and 21% experienced insufficient consideration of their colleagues. A fifth of the employees did not experience enough consideration of their boss. Significant relations between these experiences and the degree of satisfaction with work were not found. Seven (21%) of the present workers wished (more) job modifications, especially more personal time management, the opportunity to work at home, or (more) adaptations of the workplace.

Absence due to illness at present was reported by 17% of the respondents; ten per cent were absent because of factors related to the SCI. Half of the working respondents recently had contacts with work professionals regarding their health at work. Three of them still received support from the rehabilitation team. Six (18%) wished more contacts with work professionals, and half of them was in need of more support from the rehabilitation team. This subgroup with unmet needs also seemed less satisfied with the job, but the differences were not significant. Two persons were looking for a different job with better working conditions, flexible working hours or better salary.

Discussion

Return to work is regarded as one of the most important long-term rehabilitation goals[4,5]. In this study we found that a large number of people with SCI are able to work, which was not associated with SCI-specific factors. The educational level was a significant indicator of vocational outcome. The personal experiences and unmet needs of the workers reveal that long-term support is indispensable to keep them at work.
The group of patients under study completed a standard multidisciplinary rehabilitation programme including education, training and counselling. The study group was a representative cohort of patients with traumatic SCI with vocational potential. As Dutch patients with traumatic SCI usually are admitted to the rehabilitation centre and have equal rehabilitation and reintegration opportunities, generalisation of the results is possible to the whole population with traumatic SCI in The Netherlands.

As the majority of patients with a traumatic spinal cord injury are relatively young, attention to social and vocational reintegration is of particular importance, not just to the patients themselves but also from a wider social point of view[9]. Despite the serious consequences of the SCI regarding ambulation, functional independence and social continence, this should never be a reason to exclude people with SCI from the labour market without exploring vocational possibilities. Participation in the employment process of chronically disabled has been an important point of political interest in The Netherlands for the last decade and equal opportunities for persons with a chronic disease are laid down by law. Individual job counselling and vocational services are formally available for all persons with vocational handicaps. However, many studies have shown that the chronically disabled still experience problems and are often insufficiently enabled to participate in the employment process[2,6,7].

An outline is given of the health status, work-related abilities and dependence on help, to reveal factors which play a role in reintegration in work in four different SCI groups. Regarding the number of work-related disabilities, the extra time needed for self-care, and the degree of perceived physical functioning, the completeness of the lesion differentiated better than the level of the lesion. In view of these outcomes, the impact on the level of activities is larger for people with complete SCI. The high dependence score and dissatisfaction with self-care abilities of persons with complete tetraplegia illustrate the dependence on others with several daily activities. The results on the other perceived health items and life satisfaction domains were not associated with the type of SCI. And what is important for this study: also the vocational outcome did not show significant difference between the subgroups.

The percentage of 60% who were currently being employed in the present study was higher than expected. The variation in study samples in terms of demographic and injury-related characteristics, makes it difficult to compare results of different studies. In a Dutch multi-centre study [12] Thomassen *et al.*

reported that 37% of pre-injury workers were gainfully employed after the SCI, which was lower than the outcome in this study. The recruitment of participants was comparable. Persons in our study group were slightly younger with little more incomplete lesions and the time since injury was on average longer. Other factors such as socio-economic and cultural circumstances were assumed to play a role, but were not analysed in this study. We were not able to identify significant SCI-specific indicators of vocational outcome several years after the SCI. The educational level turned out to be an important factor. This asks for an extensive evaluation of opportunities for education and vocational re-training during the vocational rehabilitation.

In this study two-thirds of persons at work underwent on average extensive changes in working hours. Employees reduced their average working hours to two-thirds and self-employed workers even to half of their former hours. Financial consequences were often at least partially compensated by benefits from the Work Disability Act, which makes it attractive to carry on working. Job adjustments are often indispensable to return successfully to former and new jobs. Despite small numbers of patients, several differences in the interventions and experiences can be found between persons who kept working at the same employer and those who changed to a different employer. The first group reintegrated relatively fast with various adjustments and loss of working hours. The employer is obliged to support all measures needed to reintegrate in work. Persons who had to find a different employer received more vocational re-training and needed more time to return to work, so long-term counseling of this group is essential. However, it seems that working hours are less often reduced, people are less dependent on the Work Disability Act, and more satisfied with their job, which confirms the assumption that new jobs are less physically demanding and match better with the disabilities. In view of these findings we assume that persons who change to a different employer have better chances to keep at work in the long run. Prospective studies are necessary to test this hypothesis.

The main goal of the Vocational Handicap Research Programme which was developed by *TNO Arbeid* (Dutch Organisation for Applied Scientific Research), was to describe the working conditions and experiences of chronic disabled people with various diagnoses, to create a more positive image of their capabilities and improve interventions[2,6]. The personal experiences of working respondents in our study were reasonably positive. Most of them were fairly satisfied or satisfied with their jobs and that is comparable to the experiences of other disabled workers[6]. Nevertheless, the number of negative experiences associated with work such as mental strain, working under pressure, insufficient consideration of colleagues and bosses, and absence due to illness, are relatively high and should not be underestimated. As in other studies of the research programme of *TNO Arbeid* a substantial number of workers wished more adjustments and contacts with professionals. Employees are less satisfied if they feel a need

for further adaptations in the workplace and experience negative social effects due to their disorder[2]. The group of ageing SCI disabled is even more at risk of not sustaining employment, because of early reduction of physical condition[4,11]. This asks for ongoing efforts of professionals to keep this group with SCI at work, with interventions that fit personal requirements. More freedom in personal time management and the opportunity to work at home seem preferable.

In-depth interviews are needed to gain more insight in the personal experience of those who returned to work following a SCI, to enhance the quality of individual counselling and effective interventions. Vocational guidance should not be restricted to the rehabilitation and following reintegration period, but to be continued in the long run to keep the people with SCI at work.

Appendix

Questionnaire for workers as part of the Vocational Handicap Research Programme of *TNO Arbeid* (items not used in this study are in italics):

1. Disease-specific items:
   - Disabilities regarding work-related activities
   - Dependence on help with self-care, domestic activities, transport
   - *Complaints / symptoms*
2. Health: assessment of health perception on 9 dimensions (RAND 36)
3. Income
4. Educational level
5. Pre-injury employment situation: type of job, job contract, working hours
6. Current employment situation: type of job, job contract, working hours
7. Job modifications:
   - Change of job or employer
   - Material and immaterial adaptations of the job
8. Opinions about the current working conditions and social atmosphere:
   - Job satisfaction
   - Personal experiences regarding the job
   - Accessibility and transport
   - Relationship with colleagues and boss
   - Possibilities for promotion
   - Influence of job on health
   - Wish for (more) job modifications
   - Absence due to illness
   - Contacts with work professionals
   - Wish for (more) contacts with work professionals
   - Looking for another job
9. *Situation of those who stopped working*

References

1. Pentland W, Harvey AS, Smith T, Walker J. The impact of spinal cord injury on men's time use. Spinal Cord 1999;37:786-792.
2. Andries F, *et al*. Vocational perspectives and neuromuscular disorders. International Journal of Rehabilitation Research 1997;20:255-273.
3. International Classification of Functioning, Disability and Health ICF). Geneva: World Health Organisation, 2001
4. Krause JS. Employment after spinal cord injury. Arch Phys Med Rehabil 1992;73:163-169.
5. Noreau L, Dion S-A, Vachon J, Gervais M, Laramée M-T. Productivity outcomes of individuals with spinal cord. Spinal Cord 1999;37:730-736.
6. Wevers CWJ, Brouwer OF, Padberg GW, Nijboer ID. Job perspectives in facioscapulohumeral muscular dystrophy. Disability and Rehabilitation 1993;15:24-28.
7. Schoppen T, Boonstra AM, Groothoff JW, Vries J de, Göeken LNH, Eisma WH. Employment status, job characteristics and work related health experience of people with lower limb amputation in The Netherlands. Arch Phys Med Rehabil 2001;82:239-245.
8. Murphy G, Brown D, Athanasou J, Foreman P, Young A. Labour force participation and employment among a sample of Australian patients with spinal cord injury. Spinal cord 1997;35:238-244.
9. Siösteen A, Lundqvist C, Blomstrand C, Sullivan L, Sullivan M. The quality of life of three functional spinal cord injury subgroups in a Swedish community. Paraplegia 1990;28:476-488.
10. Berghammer A, Gramm M, Vogler L, Schmitt-Dannert H-H. Investigation of the social status of paraplegic individuals after medical rehabilitation. Spinal cord 1997;35:493-497.
11. Conroy L, McKenna K. Vocational outcome following spinal cord injury. Spinal Cord 1999;37:624-633.
12. Tomassen PCD, Post MWM, Asbeck FWA van. Return to work after spinal cord injury. Spinal Cord 2000; 38:51-55.
13. Goldberg RT, Freed MM. Vocational development of spinal cord injury patients: an 8-year follow-up. Arch Phys Med Rehabil 1982;63:207-210.
14. DeJong G, Branch LG, Corcoran PJ. Independent living outcomes in spinal cord injury: multivariate analyses. Arch Phys Med Rehabil 1984;65:66-73.
15. DeVivo MJ, Rutt RD, Stover SL, Fine PR. Employment after spinal cord injury. Arch Phys Med Rehabil 1987;68:494-498.
16. Taricco M, et al. The social and vocational outcome of spinal cord injury patients. Paraplegia 1992;30:214-219.

17. Levi R, Hultling C, Seiger A. The Stockholm spinal cord injury study: 4. Psycho-social and financial issues of the Swedish annual level-of-living survey in SCI subjects and controls. Paraplegia 1996;34:152-157.
18. Post MWM, Witte LP de, Asbeck FWA van, Dijk AJ van, Schrijvers AJP. Predictors of health status and life satisfaction in spinal cord injury. Arch Phys Med Rehabil 1998;78:395-402.
19. Clayton KS, Chubon RA. Factors associated with the quality of life of long-term spinal cord injured persons. Arch Phys Med Rehabil 1994;75:633-8.
20. Post MWM, Dijk AJ van, Asbeck FWA van, Schrijvers AJP. Life satisfaction of persons with spinal cord injury compared to a population group. Scand J Rehab Med 1998;30:23-30.
21. Zee K van der, Sanderman R. Het meten van een algemene gezondheids-toestand met de RAND-36: een handleiding. Northern Centre for Healthcare Research Groningen 1993.
22. Fugl-Meyer AR, Branholm I-B, Fugl-Meyer KS. Happiness and domain-specific life satisfaction in adult Northern Swedes. Clin Rehabil 1991;5:25-35.
23. Bland JM, Altman DG. Statistics Notes: The odds ratio. BMJ 2000;320:1468 (http://bmj.com/cgi/reprintsidebar/320/7247/1468??eaf).

Chapter 7

Participation and satisfaction after spinal cord injury: results of a vocational and leisure outcome study

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Submitted

Abstract

Objective: Insight in the changes in participation in vocational and leisure activities and satisfaction with the current participation level of people with spinal cord injuries (SCI) after reintegration in society.
Design: Descriptive analysis of data from a questionnaire.
Setting: Dutch rehabilitation centre with special department for patients with spinal cord injuries.
Methods: Descriptive analysis of data gathered by a mailed questionnaire, which was returned by 57 individuals (response 83%) with a traumatic SCI, aged 18 to 60 years, admitted to the rehabilitation centre from 1990 to 1998.
Results: Participation expressed in terms of hours spent on vocational and leisure activities changed to a great extent after the spinal cord injury. This was mainly determined by a large reduction of hours spent on paid work. While 60% of the respondents currently have a paid job, many changes took place in the type and extent of the job. Loss of work was partially compensated with domestic and leisure activities. Sports activities were reduced substantially. The change in participation level and compensation for the lost working hours was not significantly associated with the level of work-related disabilities or SCI specific health problems. As was found in other studies most respondents were satisfied with their lives. Determinants of a negative life satisfaction several years after the SCI were not easily indicated. Reduced quality of life was particularly related to a unsatisfactory work and leisure situation. Dissatisfied people reported more unmet needs regarding reintegration interventions.
Conclusions: Changes in participation after a SCI are mainly explained by reduction of working hours. Some of the SCI disabled are successful in compensating for their loss of work. Focus on the vocational and leisure situation after the rehabilitation period might enhance a satisfactory participation. Information about the unmet needs during the reintegration process can help professionals to guide people with SCI through the complex reintegration procedures.

Introduction

Nowadays most people with spinal cord injuries (SCI) learn to adapt to the fundamental changes in their lives. A significant number of them achieve independence in daily activities. To enhance reintegration into society, participation in work and leisure activities are of important value. Active involvement in activities and roles is strongly related to health and well being[1] and a high level of social activities leads to a better quality of life[2,3]. This study was conducted to provide insight in the outcomes of vocational and leisure participation of people with SCI, several years after the injury.

From a social point of view return to work is regarded as one of the most important outcomes of reintegration in society[4,5]. It gives people a social status and meaning to life, and enables them to be financially independent. From other studies we know that the chances to resume work are restricted for patients with chronic diseases and disabilities[6-8]. Working rates for people with SCI vary from 31 to 48% in recent studies[9-13]. Factors related to the success of vocational reintegration in work are age, education level, realistic expectations, motivation, pre-injury type of job and disease-specific problems and disabilities[3,4,9,14-16].

For those people who were not able to reintegrate in work, participation in non-vocational activities must also be considered as a successful rehabilitation outcome. Very few studies have described the types of post-injury activities and roles other than traditional employment[1,3,5,17]. The assessment of these non-vocational outcomes is more difficult, since those activities are more complex to quantify in everyday life. In a Swedish study the majority of subjects had succeeded in finding new interests and hobbies or adapting pre-injury leisure activities to the disability[3]. A major shift in time use occurred from time spent on social activities to personal care activities.

Attaining an acceptable quality of life can be seen as the ultimate goal of rehabilitation. Several objective and subjective determinants of quality of life after a SCI were studied in literature[2,3,11,18-23]. Some authors found that the life satisfaction among persons with SCI is relatively good and in a few studies even better than their peers[21,22]. Other findings indicate that people with SCI who live at home report a lower level of satisfaction with life[20]. Post *et al*. also found a lower general life satisfaction than in the Dutch reference group, but some differences disappeared after adjustment for age and marital status[2]. Satisfaction with the vocational situation is usually low[11,20]. For persons who returned to work after the SCI, this can be explained by unrewarding, poor-quality jobs[2]. In a previous study on vocational reintegration we found a reasonably good job satisfaction[14]. Information about the satisfaction with non-vocational activities is rare[1,3]. To improve the rehabilitation programmes, it is important to know which specific problems due to the SCI interfere with a satisfactory participation.

The rehabilitation team can prepare patients and family and teach them how to cope with these matters.

In this study an assessment was done of the changes in time use and actual reintegration in vocational and leisure activities, several years after the onset of the SCI. Results of life satisfaction were presented, especially regarding the vocational and leisure situation. Experiences of people with SCI regarding the support from the rehabilitation team and job professionals during the reintegration process was analysed.

Methods

Patients

In this study we focused on patients with traumatic spinal cord injury, aged 18 to 60 years, living in the community, who were admitted to the Centre for Rehabilitation Beatrixoord two to twelve years before the assessment. Of 89 eligible candidates 16 patients were excluded: four patients deceased, three had serious psychiatric problems, one was discharged to a nursing home, two finished their rehabilitation program in another rehabilitation centre and six were foreigners with difficulties with the Dutch language. Seventy-three patients were included in the study. Of four patients addresses were not found and they were lost for follow-up. To 69 patients a questionnaire was sent. The questionnaire was filled in and returned by 57 patients, which means a response of 83%.

Questionnaire

Data on participation and satisfaction of the study group and factors that might have influenced these outcomes, were gathered from a questionnaire, which was developed for this study. We defined participation as the results of reintegration in vocational and leisure activities. Vocational participation consisted of activities related to paid and non-paid work, school and housekeeping. Activities such as hobbies and sports were indicated as leisure participation. To assess the time spent on these participation activities before and after the SCI we used the Utrechtse Activiteiten Lijst. Besides, we asked for an estimation of the time needed for self-care in minutes pre- and post-injury.

Our questionnaire also consisted of important parts of a questionnaire developed by *TNO Arbeid* (Netherlands Organisation for Applied Scientific Research) Vocational Handicap Research Programme. *TNO Arbeid* validated their questionnaire in several research projects and reported good reliability of the test[6,7]. Data became available on the employment situation of this study group both pre-injury and after the reintegration. Respondents were asked to report the changes in type of job and working hours, vocational re-training, job modifications, contacts with work professionals, income and their opinion on the working conditions and social atmosphere. The TNO assessment also included scales regarding the educational level (score 1-8),

work-related disabilities (score 0-54) and dependence on help (weighed score 0-42). Changes in the type of hobbies and sports were assessed as well as the support of the rehabilitation team in developing new leisure activities.

Life satisfaction was considered as a main outcome measure and assessed by the Fugl-Meijer Life Satisfaction Questionnaire (LSQ)[24]. The LSQ measures general life satisfaction and satisfaction on eight life domains: self-care ability, leisure situation, vocational situation, financial situation, sexual life, partnership relations, family life and contacts with friends. We used the Dutch version of the scale, translated and validated by Post et al[11,23]. LSQ item scores range from 1 (=very dissatisfying) up to 6 (=very satisfying) and mean item scores were used. In order to differentiate between "satisfied" from "not satisfied " persons we also dichotomised the scores of the general life satisfaction in respectively grades 5 - 6 (satisfying and very satisfying) and grades 1 to 4 (very dissatisfying to little satisfying).

Several personal, SCI-specific and work-related factors were studied for their relationship with the change in participation and satisfaction. Regarding the SCI-specific variables the type of SCI was defined according to the standards for neurological and functional classification by the American Spinal Injury Association. We used a validated scale with eight health problems related to SCI, experienced in the last four weeks before assessment[21]: respiratory problems, pain, spasms, contractures, excessive sweating, oedema, pressure sores, urinary tract infections. A health problem score 0 to 8 was obtained by counting all the "yes"-answers on a two-point scale.The ability to walk and the level of continence for urine were both assessed on a three-point scale.

Systematic assessment of expectations of all patients with spinal cord injuries during the rehabilitation period was started in 1988 in the SCI department. It concerned expectations of patients and the team regarding functional outcome in several domains. For this study the question about coping were selected: "Do you expect to cope with the handicap?" Possible answers were "yes", "no" and "uncertain". We used the data of the final assessment after admission to the rehabilitation centre.

Analysis

Descriptive statistics were performed using the Statistical Product and Service Solutions (SPSS). The hours spent on several vocational and leisure activities before the SCI and at the moment of assessment were compared with a paired *t*-test. Analyses of variance and multiple comparison of the groups were used to compare the subgroups with different levels of change in participation. Differences between satisfied and not satisfied groups regarding satisfaction on eight life domains were tested using independent sample *t*-test, and regarding personal, SCI-specific and work-related variables univariate logistic regression analyses were used. Odds ratios were presented and the significance level was chosen as $p<0.05$.

Results

The study group of 57 respondents consisted of 52 males (91%) and 5 females. Their age at the moment of the SCI ranged from 18 to 59 years with a mean of 33 years. The time elapsed since injury varied from 29 to 140 months with a mean of 84 months. Forty percent of the injuries were caused by traffic accidents, 23% by industrial accidents, and 37% by sports and private accidents. Six patients had a complete tetraplegia, 17 patients had an incomplete tetraplegia, 20 patients a complete paraplegia and 14 an incomplete paraplegia.

The group of patients who returned the questionnaire was compared to the group who gave no response (n=12). There were no significant differences regarding age, gender and type of SCI. The most remarkable difference between the group of respondents and non-respondents was the percentage of patients working pre-injury. In the group of respondents 86% worked at the moment of SCI versus 42% in the group of non-responders. In the group of non-responders the time elapsed since the SCI was on average longer than in the group of responders.

Changes in participation

The results on the "Utrechtse activiteitenlijst" pre-injury and now are presented in Table 1. Hours spent on paid work determined the total time use to a great extent. The most remarkable change was found in the average working hours with a decrease of more than 20 hours a week. Hours spent on sports significantly diminished as well. The total vocational and leisure participation of the study group was reduced with 40%. The variance in time use after the SCI was more pronounced than pre-injury. Significantly more time was spent on self-care activities, which changed from about half an hour a day pre-injury to a mean of 70 minutes a day at the moment of assessment.

At the moment of the SCI 49 of the 57 respondents (86%) had a job and most of them worked full-time (median 40 hours/week). Five males with a mean age of 21 years went to school. Three males were out of work for a long time. Of the group of 49 pre-injury workers 33 patients (67%) successfully returned to paid work. Four of them stopped working several years after the reintegration. Eighteen of the 29 reintegrated persons (62%) worked less hours now than before the SCI. The least number of working hours was lost by the group that changed to a different employer. All five students graduated in the meantime, so study hours diminished on the whole. Two respondents currently were active in vocational training. At the moment of assessment 34 respondents (60%) were occupied including 29 of the pre-injury working patients and all five students. The number of persons doing voluntary work did not change, but the time spent on it slightly increased.

Table 1. Vocational and leisure participation expressed in hours per week (mean (SD)) before the SCI and at the moment of assessment analysed by paired *t*-test (*n*=57).

Participation	*Pre-injury* hrs/week (SD)	*Now* hrs/week (SD)	*t*
Paid work*	41.6 (21.2)	19.5 (20.3)	6.3
Study	3.4 (9.8)	1.0 (4.3)	1.7
Housekeeping	5.2 (6.3)	7.3 (8.3)	1.7
Small jobs at home*	5.1 (4.8)	3.3 (5.6)	2.2
Voluntary work	1.4 (3.0)	2.1 (4.2)	1.0
*Total vocational participation**	57.2 (16.3)	33.5 (21.6)	7.9
Sports*	4.0 (5.7)	1.2 (2.4)	3.4
Clubs	0.8 (1.9)	0.8 (1.9)	0.4
Other leisure activities	4.9 (7.6)	5.2 (8.0)	0.4
Total leisure participation	9.8 (9.1)	7.2 (8.5)	1.9
*Total participation**	65.9 (18.1)	39.6 (23.3)	8.8
Time for self-care*	3.3 (2.5)	8.1 (5.3)	7.4

* $p<0.05$

Most of the respondents needed help with domestic activities after the SCI, at least partially, and especially with heavy work and shopping. However, one-third of the study group spent more hours on housekeeping than pre-injury and 17 respondents became active in a role as homemaker during more than eight hours a week, *versus* 13 pre-injury. More than half of them lost their paid job or had a substantial reduction of working hours. Of 57 respondents 72% reported loss of hobbies. Handicraft and several kinds of sports like football, skating and cycling were mentioned most often. About half of the study population found new hobbies, varying from personal computer activities and archery to hobbies adapted to the handicap, such as wheelchair dancing or wheeling. Twenty-one SCI disabled persons (37%) were currently active in sports and 60% before the SCI, with a mean of three hours per week now *versus* five hours pre-injury.

Two-thirds of them participated in types of sports different from the situation before the SCI.

Factors related to changes in participation

We divided the study group into four subgroups with different levels of change in participation and analysed several factors which might be associated. It concerned two subgroups currently working, who either kept full-time jobs (A) or changed to part-time jobs of 28 hours at the most (B), and two subgroups without work, who succeeded (C) or failed (D) in compensating for their lost participation activities. Respondents in subgroup (*n*=20) currently worked on average 43 hours a week (median 40, range 29-70), and they also worked 43 hours a week pre-injury. Persons in subgroup B (*n*=14) changed to smaller jobs with a mean of 15 hours (median 15, range 4-28) *versus* 40 hours pre-injury. The total hours spent on vocational and leisure activities per week hardly changed in subgroup A from an average of 68 to 64 hours a week, and was halved in subgroup B from an average of 61 to 28 hours a week. Persons in subgroup C (*n*=10) compensated their lost working hours with one or more specific other activities, like significant involvement in the housekeeping, leisure activities or voluntary work. They currently spent a mean of 38 hours on participation activities a week *versus* 75 hours pre-injury. Respondents in subgroup D (*n*=13) lost participation in all activities and were active during 16 hours a week *versus* 60 hours pre-injury. The proportion leisure hours of the total hours spent on vocational and leisure activities of subgroups A - D was respectively 12%, 25%, 32% and 44%.

Comparison of the subgroups regarding several personal and SCI-related variables is shown in Table 2. Multiple comparison of the groups showed that full-time workers (A) were significantly younger than the workers with extensive reduction in working hours (B). Respondents currently working in subgroups A and B were significantly higher educated than those without work (C and D). The level of change in participation was not associated with the scores on work-related disabilities and SCI-specific health problems. Of the two subgroups with respondents who stopped working, the differences regarding the pre-injury participation level, the dependence on help, and the extra time spent on self-care were not significant.

Satisfaction with the vocational and leisure situation

In our study population 38 persons with SCI (67%) were satisfied or very satisfied (grades 5 and 6) with their lives in general, according to the Life Satisfaction Questionnaire. Retrospectively 18% of those 38 satisfied respondents were even more satisfied than before the SCI. All 19 respondents who were little or not satisfied with their lives (grades 1 to 4) experienced a decline of satisfaction in comparison with pre-injury. The satisfaction within the different domains according to the Life Satisfaction Questionnaire was given in Table 3. The highest mean item scores of

satisfaction were found regarding the leisure situation and social roles. Comparison of the subgroups with persons who were satisfied and not satisfied with their lives (*t*-test for groups), revealed a significantly lower satisfaction with the work and leisure situation of the dissatisfied group. Fourteen of 19 respondents being not satisfied with their life (74%) had a dissatisfying work or leisure situation, and nine (47%) were not satisfied with both the vocational and leisure participation. Comparison of the groups with different levels of change in participation showed that the satisfaction with the vocational situation was significantly lower in subgroup C, but not lower in subgroup D (not in table). The satisfaction with the leisure situation and the general life satisfaction did not show any difference between the subgroups.

Table 2. Comparison of subgroups with different levels of change in participation (*n*=57) regarding personal and injury-related factors (mean (SD)), using analyses of variance.

	A *At work, still full-time job* *n*= 20	*B* *At work, part-time job* *n* = 14	*C* *No work, but com-pensation* *n* = 10	*D* *No work, no com-pensation* *n* = 13	*Total* *n*=57
Age now * (years)	35.6 (8.4)	42.4 (9.6)	47.7(10.3)	39.1(12.1)	40.2(10.6)
Educational level * (0-8)	4.5 (1.6)	4.9 (2.0)	3.6 (1.4)	3.5 (1.5)	4.2 (1.7)
Pre-injury participation	68.1(15.5)	61.2 (7.5)	75.1(12.8)	60.3(28.5)	65.9(18.1)
Health problems (0-8)	2.0 (1.3)	2.4 (1.2)	1.8 (1.2)	1.7 (1.7)	2.0 (1.4)
Disabilities (0-54)	14.3 (7.8)	18.0 (5.3)	17.5 (5.1)	17.1 (5.5)	16.4 (6.4)
Dependence (0-42)	7.2 (11.2)	9.4 (7.7)	8.8 (12.3)	15.1(16.1)	9.8 (12.1)
Extra time for self-care	35.5(41.0)	36.9(27.0)	69.5(52.3)	31.2(39.3)	40.6(41.6)

* $p<0.05$

Table 3. The life satisfaction on eight life domains (mean item scores (SD)) of the study group (*n*=57) and comparison of satisfied and unsatisfied subgroups analysed with independent sample *t*-test.

LSQ	*Total* *n*=57	*Satisfied* *n*=38 (67%)	*Not satisfied* *n*=19 (33%)	*t*
Self-care ability *	4.39 (1.36)	4.82 (1.06)	3.53 (1.50)	3.7
Leisure situation *	4.70 (1.31)	5.21 (0.78)	3.68 (1.57)	4.9
Vocational situation *	4.28 (1.61)	4.73 (1.26)	3.47 (1.87)	2.8
Financial situation	4.33 (1.20)	4.55 (1.03)	3.89 (1.41)	2.0
Sexual life *	3.26 (1.59)	4.00 (1.32)	2.18 (1.33)	4.4
Partnership relation	4.74 (1.60)	4.92 (1.61)	4.43 (1.60)	0.9
Family life *	5.05 (1.12)	5.44 (0.70)	4.29 (1.38)	3.6
Contacts with friends	4.96 (1.27)	5.21 (0.93)	4.47 (1.68)	2.1

* $p<0.05$

Factors related to life satisfaction

Indicators of life satisfaction were presented in Table 4. Looking at the earlier expectations at discharge from the rehabilitation centre we found that 81% of the patients expected to learn to cope with their handicaps. The respondents with uncertain expectations regarding coping seemed more often dissatisfied with the quality of life at the moment of assessment, but these differences were not significant in the univariate logistic regression analyses. Being employed was not associated with general life satisfaction. Significant indicators of life satisfaction were not found.

Support and unmet needs

Information about the support and professional interventions during the rehabilitation process and the period thereafter was assessed as a part of the questionnaire. Sixteen persons (28%) reported that they received help from the rehabilitation team in finding new hobbies or sports. The occupational therapist, physical therapist and leisure therapist were the main professionals in supporting the uptake of new leisure activities. Most of the activities regarding vocational reintegration took place after the rehabilitation period. Of 49 patients with a job pre-injury 16 respondents (33%) reported participation in vocational re-training. Thirteen (81%) of them were satisfied with the training. Thirteen of the 34 working respondents (38%) returned to

paid work without supplementary benefit and 62% worked with benefit from the Work Disability Act. The respondents who were not working (anymore) all received social security benefit, most of them full benefit from the Work Disability Act.

Table 4. Comparison of satisfied and unsatisfied subgroups (*n*=57) related to the expectations regarding personal and injury-related factors and participation, with univariate logistic regression analyses (odds ratios (OR)).

	Satisfied *n*=38 (67%)	*Not satisfied* *n*=19 (33%)	OR	*p*-value
Personal factors				
Expected to cope: *n* (%)				0.171
-Yes	27 (69)	12 (31)	2.8	
-No	4 (44)	5 (56)		
Educational level: *n* (%)				0.096
-Low	23 (77)	7 (23)	2.6	
-Middle/high	15 (56)	12 (44)		
SCI-specific factors				0.187
Type SCI: *n* (%)	3 (50)	3 (50)	1.0	
-Compl tetraplegia	9 (53)	8 (47)	1.1	
-Incompl tetraplegia	17 (85)	3 (15)	5.7	
-Compl paraplegia	9 (64)	5 (36)	1.8	
-Incompl paraplegia				
Pain related to SCI: (%)				0.065
-Yes	18 (56)	14 (44)	0.3	
-No	20 (80)	5 (20)		
Walking: *n* (%)				0.351
-Yes/ with difficulty	17 (61)	11 (39)	0.6	
-No	21 (75)	8 (25)		
Continent: *n* (%)				0.708
-Yes	20 (69)	9 (31)	1.2	
-With difficulty/ no	18 (64)	10 (36)		
Participation level: *n* (%)				0.655
-A: full-time job	14 (70)	6 (30)	1.0	
-B: small job	8 (57)	6 (43)	1.8	
-C: no job, comp.	8 (80)	2 (20)	0.6	
-D: no job, no comp.	8 (62)	5 (38)	1.5	

* $p<0.05$

In 74% of the 34 present work situations job modifications took place. Material adaptations included personal aids and adapted furniture or toilet facilities. Of the immaterial adaptations personal time management (planning your own working day) was often mentioned and part of the respondents was able to work at home. Half of the working respondents recently had contacts with professionals regarding their health at work. Three of them still received support from the rehabilitation team. Fourteen respondents (25%) reported they wished more contacts with professionals, and half of them needed more support from the rehabilitation team. The group of 19 persons who judged the quality of life as dissatisfying, reported relatively more unmet needs regarding re-training, job modifications and contacts with professionals than the satisfied respondents.

Discussion

The most important goal of rehabilitation is to enable disabled persons to return to independent and satisfactory lives in their community. In order to provide successful rehabilitation programmes based on realistic goals, insight is needed in the prognosis of participation and satisfaction following a SCI. In this study we found that participation level expressed in terms of hours spent on vocational and leisure activities changed to a great extent after the spinal cord injury, which is mainly explained by reduction of working hours. The majority were able to return to work or compensate the time formerly spent on work with other activities. As most of the respondents were satisfied with their lives, we assumed that the coping process was often successful. However, a reduced quality of life was particularly associated with a unsatisfactory vocational and leisure situation and more unmet needs regarding support from professionals. Attention to participation issues after the rehabilitation might improve life satisfaction following SCI.

The cohort of patients under study completed a standard multi-disciplinary rehabilitation programme including education, training and counselling, based on goals set by the rehabilitation team in agreement with the patient[25]. As the response rate is high (83%), generalisation is possible to the whole population with traumatic SCI in The Netherlands, who has equal rehabilitation and reintegration opportunities. Various outcome measures are used in rehabilitation research[2]. Objective indicators are provided by the assessment of physical and psychological functioning, employment status or income. More subjective approaches focus on the person's satisfaction with those aspects of life, thought to be affected by the particular disability under study. We used quantitative results of vocational and leisure participation as well as life satisfaction as our main outcome measures.

Preceding the SCI this study group was very active compared to the Dutch population and spent on average more than 40 working hours a week

pre-injury. It concerned a relatively high number of self-employed workers and persons who extended their regular jobs with jobs on the side in evening hours. As we presented in our study on vocational reintegration after SCI their early expectations regarding return to work at discharge from the rehabilitation centre were high[14]. Nearly 60% of our study population was working at the moment of assessment after the SCI, which is higher than in comparable studies done in the last decade [9-13]. Nevertheless, we found a reduction of more than 50% of the total working hours after their reintegration. The least reduction of working hours was found if the subjects changed to other jobs that match better with their disabilities. To prevent large decrease of working hours it is essential to provide opportunities for jobs that fit with physical changes and inconveniences[14]. More patients became active in domestic activities despite increased dependence on help with at least part of the housekeeping. The majority of the SCI disabled lost former hobbies and sports activities and half of the study group created new leisure activities, part of them with help of the rehabilitation team. As was expected, a lot more time was spent on self-care. Moreover, it is good to realise that people with SCI generally need a lot of time for self-care on several planned and unplanned points in time. We think that the extra time that is needed for all inconveniences outdoors due to the continence problems and reduced mobility, usually is underestimated.

More detailed analysis of the time use of respondents showed remarkable variation in the extent of changes in participation. Comparison of respondents with jobs with minor change (A) and extensive (B) loss of hours, indicates that the loss of participation hours of part-time workers is more than just the reduction of their working hours. Some of the part-time workers make every effort to keep at work for social and personal reasons, even if this leads to loss of other activities. SCI-specific factors associated with these different outcomes were not found. The working respondents were significantly higher educated. Some of those who failed to reintegrate in work compensated the time formerly spent on work with various other activities. A few of them changed roles with their partners and became homemakers in stead of breadwinner. Others expanded their activities to voluntary work. Significant relations with the compensation for lost working hours were not found. The pre-injury activity level and dependence on help might have played a role in a larger study group. We were not able to take potential factors such as coping strength into account and we conclude that a prospective and more qualitative study is needed to analyse these subjective factors.

As in other studies on the quality of life among persons with chronic diseases most respondents of our study were satisfied with their lives[21,22]. In contrary to what one might expect, a lot of persons with serious disabilities were able to cope with their handicaps. Some of the study group were even more satisfied than before the injury.

Table 5. Proportion being satisfied (grades 5 and 6) and mean life satisfaction scores of this study group compared to Swedish reference group in study of Bränholm *et al.*[27] and Dutch SCI group and reference group in study of Post *et al.*[23].

LSQ	*This SCI study group* *n*=57 % satisf (CI95%)	Swedish reference group *n*=163 % satisf (CI95%)	*This SCI study group* *n*=57 mean item score (CI95%)	Dutch SCI group *n*=318 mean item score	Dutch reference group *n*=507 mean item score
My life as a whole	67% (53-78)	73% (65-80)	4.60 (4.33-4.87)	4.41	4.68
Self-care ability	67% (53-78)	94%* (91-98)	4.39 (4.04-4.74)	4.26	5.60#
Leisure situation	77% (64-87)	56%* (48-64)	4.70 (4.37-5.03)	4.41	4.73
Vocational situation	66% (51-79)	59% (51-66)	4.28 (3.81-4.75)	3.80	4.37
Financial situation	61% (48-74)	47% (39-55)	4.33 (4.02-4.64)	4.10	4.23
Sexual life	29% (16-45)	67%* (59-74)	3.26 (2.77-3.75)	3.13	4.14#
Partnership relations	77% (60-88)	77% (70-83)	4.74 (4.23-5.25)	4.88	4.46
Family life	83% (74-97)	82% (77-89)	5.05 (4.72-5.38)	4.80	4.43#
Contacts with friends	83% (74-97)	59%* (51-66)	4.96 (4.63-5.29)	4.74	4.91

* possible differences between this SCI study group and Swedish reference group $p<0.05$
# possible differences between this SCI study group and Dutch reference group $p<0.05$

Life satisfaction is considered to embody an assessment of life as a whole based on how well personal goals match with personal achievement [19]. Adjustment to the consequences of a spinal cord injury is an immense complex procedure and considerable research effort has been made to assess those factors which may be associated with good or bad adjustment[18,19,21].

Comparison of the results of life satisfaction in our study with those of Bränholm *et al.*[27] and Post *et al.*[23] is summarised in Table 5. As standard deviations were lacking in their publications it was not possible to compare the studies statistically. A large proportion of our study group was particularly satisfied with their leisure situation and social roles. The majority of the respondents succeeded in adapting pre-injury leisure activities to the disability or finding new hobbies. Unlike other studies[20,23] the mean satisfaction with the vocational situation of our study group was also relatively good and comparable with the Dutch reference group in the study of Post. An explanation for this is not easily given. Socio-economic and cultural differences may play a role, but analysis regarding these factors was not possible. The SCI subjects in both Dutch studies were on average less satisfied with their self-care abilities and sexual life than the Dutch and Swedish reference group.

Life satisfaction in this study was not associated with being employed in the long run. It illustrates that most of the SCI disabled gradually adjust to a situation without paid work. However, it was remarkable to find that the subgroup who was not satisfied with life in general was particularly dissatisfied with the vocational and leisure situation. Other factors related to satisfaction were not easily identified and a larger study group is needed to support the trends we found regarding SCI-related pain, educational level and coping.

Increasing the proportion of persons in gainful employment seems the most realistic option to maximise the participation outcome in terms of hours spent on activities and further financial independence. Increasing the behavioural repertoire of the individual patient and creating opportunities are important interventions aiming at a successful reintegration in work[26]. The chance of return to paid work is best for persons who expect to return to work[14] and those higher educated. Focus on these aspects from the start of rehabilitation is recommended.

A substantial number of patients wished more contacts with professionals. Participation issues deserve more priority during follow-up of the multidisciplinary rehabilitation team. Ongoing stimulation and support in creating participation opportunities for people with SCI is needed to ameliorate this important aspect of quality of life. When it becomes clear that reintegration in work fails, a renewed attempt in creating leisure opportunities should be made, even if this is several years after the initial rehabilitation period. For some patients it can be too premature to focus on participation during the rehabilitation period, due to a delayed or postponed coping and acceptance process. Interventions regarding leisure participation

are comparable with the coaching of rehabilitation patients regarding other activities: training of and compensating for specific abilities of former hobbies and looking for alternatives.

In terms of future research more prospective studies are needed regarding the process of reintegration in society, which give more information with respect to the role of coping abilities, psychosocial factors, support from family and professionals etcetera. In-depth interviews with all persons involved can reveal which interventions are best to promote independence and create opportunities for participation, and in which phase they are most effective.

Conclusions

The majority of people with SCI are able to resume work and are satisfied with their work and leisure situation. However, extensive reduction of working hours takes place, which is only partially compensated. Long-term follow-up by the rehabilitation team is recommended to evaluate participation and satisfaction. Rehabilitation interventions should be made available even a long time after the SCI.

References

1. Pentland W, Harvey AS, Smith T, Walker J. The impact of spinal cord injury on men's time use. Spinal Cord 1999;37:786-792.
2. Clayton KS, Chubon RA. Factors associated with the quality of life of long-term spinal cord injured persons. Arch Phys Med Rehabil 1994;75:633-638.
3. Siösteen A, Lundqvist C, Blomstrand C, Sullivan L, Sullivan M. The quality of life of three functional spinal cord injury subgroups in a Swedish community. Paraplegia 1990;28:476-488.
4. Krause JS. Employment after spinal cord injury. Arch Phys Med Rehabil 1992;73:163-169.
5. Noreau L, Dion S-A, Vachon J, Gervais M, Laramée M-T. Productivity outcomes of individuals with spinal cord. Spinal Cord 1999;37: 730-736.
6. Andries F, *et al.* Vocational perspectives and neuromuscular disorders. International Journal of Rehabilitation Research 1997;20:255-273.
7. Wevers CWJ, Brouwer OF, Padberg GW, Nijboer ID. Job perspectives in facioscapulohumeral muscular dystrophy. Disability and Rehabilitation 1993;15:24-28.
8. Schoppen T, Boonstra AM, Groothoff JW, Vries J de, Göeken LNH, Eisma WH. Employment status, job characteristics and work related health experience of people with lower limb amputation in the Netherlands. Arch Phys Med Rehabil 2001;82:239-245.
9. Murphy G, Brown D, Athanasou J, Foreman P, Young A. Labour force participation and employment among a sample of Australian patients with spinal cord injury. Spinal cord 1997;35:238-244.
10. Berghammer A, Gramm M, Vogler L, Schmitt-Dannert H-H. Investigation of the social status of paraplegic individuals after medical rehabilitation. Spinal cord 1997;35:493-497.
11. Post MWM, Witte LP de, Asbeck FWA van, Dijk AJ van, Schrijvers AJP. Predictors of health status and life satisfaction in spinal cord injury. Arch Phys Med Rehabil 1998;78:395-402.
12. Conroy L, McKenna K. Vocational outcome following spinal cord injury. Spinal Cord 1999;37:624-633.
13. Tomassen PCD, Post MWM, Asbeck FWA van. Return to work after spinal cord injury. Spinal Cord 2000; 38:51-55.
14. Schönherr MC, Groothoff JW, Mulder GA, Eisma WH. Vocational reintegration following spinal cord injury: expectations, participation and satisfaction. Spinal Cord (in press).
15. DeJong G, Branch LG, Corcoran PJ. Independent living outcomes in spinal cord injury: multivariate analyses. Arch Phys Med Rehabil 1984;65:66-73.

16. DeVivo MJ, Rutt RD, Stover SL, Fine PR. Employment after spinal cord injury. Arch Phys Med Rehabil 1987;68:494-498.
17. Levi R, Hultling C, Seiger A. The Stockholm spinal cord injury study: 4. Psycho-social and financial issues of the Swedish annual level-of-living survey in SCI subjects and controls. Paraplegia 1996;34:152-157.
18. Taricco M, *et al*. The social and vocational outcome of spinal cord injury patients. Paraplegia 1992;30:214-219.
19. Glass CE, Jackson HF, Dutton J, Charlifue S, Orritt C. Estimating social adjustment following spinal trauma - I: who is more realistic - patient or spouse? A statistical justification. Spinal Cord 1997;35:320-325.
20. Fuhrer MJ, Rintala DH, Hart KA, Clearman R, Young ME. Relationship of life satisfaction to impairment, disability, and handicap among persons with spinal cord injury living in the community. Arch Phys Med Rehabil 1992;73:552-557.
21. Cushman LA. Spinal cord injury: 10 and 15 years after. Paraplegia 1992;30:690-6.
22. Eisenberg MG, Saltz CC. Quality of life among aging spinal cord injured persons: long term rehabilitation outcomes. Paraplegia 1991;29:514-520.
23. Post MWM, Dijk AJ van, Asbeck FWA van, Schrijvers AJP. Life satisfaction of persons with spinal cord injury compared to a population group. Scand J Rehab Med 1998;30:23-30.
24. Fugl-Meyer AR, Branholm I-B, Fugl-Meyer KS. Happiness and domain-specific life satisfaction in adult Northern Swedes. Clin Rehabil 1991;5:25-35.
25. Wade DT. Evidence relating to goal planning in rehabilitation. Clin Rehabil 1998;12:273-275.
26. Wade DT. A framework for considering rehabilitation interventions. Clin Rehabil 1998;12:363-368.
27. Branholm I-B, Eklund M, Fugl-Meyer Ks, Fugl-Meyer AR. On work and life satisfaction. J of Rehabil Sci 1991;4:29-34.

Chapter 8

General discussion

This thesis focuses on the functional outcome following spinal cord injury (SCI). It presents outcomes of a Dutch population with SCI on the level of daily activities and vocational and leisure participation. The study also provides insight in aspects of the process of inpatient multidisciplinary rehabilitation and the process of reintegration into society, as part of the continuum of care for SCI patients in The Netherlands. In all stages the role of the individual patient was emphasised and it turned out to be important in predicting functional outcome.

Knowledge of the functional outcome after SCI, and of characteristics of the process leading to these results, is indispensable to provide accurate prognostic information for the patient and family, to improve rehabilitation and reintegration programmes, and to set out health care policies. Moreover, evaluation of the performance of health care providers has become a topical subject and asks for adequate quality indicators regarding rehabilitation facilities.

In this general discussion we address the principle findings of this thesis and discuss the implications and challenges of our study. Recommendations for further research are provided.

The continuum of care

The first aim of this thesis is to give an overview of the characteristics of the population under study and to describe aspects of their process of rehabilitation, as part of the continuum of care for people with SCI in The Netherlands. The incidence was estimated to be on average 16 new patients with SCI per million per year admitted to the rehabilitation centre. Demographic differences were found between groups with traumatic and non-traumatic lesions. Nearly all patients go home after the discharge from the rehabilitation centre.

Data were analysed of a cohort of patients with spinal cord lesions admitted to the rehabilitation centre. The results of patients with traumatic SCI can be generalised to the whole Dutch population with traumatic SCI, as nearly all these patients follow a rehabilitation programme. The characteristics of patients with non-traumatic lesions are not representative for the total group of patients with non-traumatic lesions, as they are not always transferred to a rehabilitation centre. A reliable nation-wide registration of this group is not available.

Contrary to other Dutch studies we also included patients with malignant tumours with a relatively good prognosis, who were able to finish a rehabilitation programme with short-term goals. This has influenced the average length of stay at the rehabilitation centre.

Globally young males of 20 to 40 years of age are most at risk of having a traumatic SCI. As about half of the rehabilitation population have non-traumatic lesions, a second peak is found in the age group 61 to 70 years and a high number of females. Special programmes for this group are needed based on a short rehabilitation admission with short-term realistic objectives. In The Netherlands patients with acute SCI are admitted at traumatological, neurological, neurosurgical and orthopaedic departments of university and general hospitals. This variation in referring hospitals leads to fragmentation of initial medical care. As soon as the physical condition is stable they are transferred to one of the rehabilitation centres with a specialised department for spinal cord lesion care. In our opinion regional SCI-care systems should be set up in The Netherlands, consisting of close collaboration between specialised SCI departments in an academic or top-referent hospital and the rehabilitation centre. It has already been emphasised in literature that this has several benefits: more experience with the management of SCI, decrease of preventable complications and mortality, shorter lengths of stay and reduction of costs[1-3]. Rehabilitation medicine should be integrated with the continuum of care of spinal cord lesions from the very first day after injury.

The Dutch National Health Service and the private health insurances cover hospitalisation in a rehabilitation centre on medical grounds. Discharge from the rehabilitation centre is very often delayed by social circumstances. A substantial number of patients have to wait for suitable housing facilities, or for semi-independent institutions with professional help with activities of daily living available on demand. Post *et al.* already reported low satisfaction with service delivery procedures in The Netherlands and found that the discharge from the rehabilitation centre was delayed by a median time of 15.5 weeks for one third of the respondents[4]. This asks for more rapid service delivery procedures. Most services such as domestic adaptations, wheelchairs and modes of outdoor transport are provided by means of the Act on Facilities for the Handicapped (*Wet Voorzieningen Gehandicapten (WVG*), executed by local councils with medical account given by the Local Health Authority (*Gemeentelijke Gezondheidsdienst (GGD*). Procedures can be accelerated if the advice regarding required services is formulated by the rehabilitation team and replaces the often bureaucratic and time-consuming assessments by *GGD* and *WVG* officials.

Almost all patients go to their homes after their inpatient rehabilitation period. From the start of the rehabilitation programme goals are set to train skills regarding independence and facilitate personal and environmental circumstances which determine the individual's ability to live independently after discharge. After the inpatient period the patient usually follows an outpatient programme from his home for two or three days a week. This

transitional stage provides an opportunity to try out the new living situation and to evaluate the amount of care, equipment and adaptations. In this phase issues such as return to work and leisure activities become important.

As the SCI leads to chronic disabilities and an increased risk of specific health problems, the continuum of care should be prolonged after the rehabilitation period with a long-term follow-up by the rehabilitation team[5,6]. In this thesis we were not able to analyse all aspects of the aftercare of the patients, but it certainly revealed unmet needs regarding contacts with the rehabilitation team in later phases after SCI. Further research should explore the benefits regarding efficiency and quality of the entire continuum of care for people with SCI.

Activities and goal-setting

The functional outcome of patients with traumatic SCI is described in terms of independence in daily activities at discharge from the rehabilitation centre. The objectives of this study are to provide more accurate prognostic information about the independence in daily activities and to explore the role of the patient in setting realistic goals. The level of independence in daily activities at the end of the inpatient rehabilitation is not as good as expected from literature. Prediction of functional outcome after spinal cord injury is most successful if the expectations of the team and patients are combined.

The study group is a representative cohort of inpatient rehabilitation patients. All patients with traumatic SCI admitted to the rehabilitation centre in the given period were included. In this retrospective study we used the Rehabilitation Information System-Information System for spinal cord injuries (RIS-DIS) as a database, which provided extensive and detailed information on medical and functional progress. It also includes expectations of the rehabilitation team and individual patient, reported 8 weeks after admission. This information system was developed in the 1970s to evaluate the rehabilitation treatment of patients with a spinal cord injury in The Netherlands and to work out a prognostic model for functional outcome. We assessed a basic set of relevant daily activities, but we realised that it was not simply comparable to scales with accepted validity and reliability such as the Barthel Index[7]. Further research has to be done to examine the clinimetric properties of the RIS-DIS for more extensive scientific purposes.

Early prediction of neurological and functional outcome of SCI is useful in informing the patient and family and making decisions about treatment. Functional prognosis is usually based on the initial level and extent of the lesion. However, the level of independence in daily activities which was achieved in this study was not as good as expected, based on the theoretical models. Other factors such as co-morbidity, spasticity, pain, motivation and coping also seem to play an important role and are subject to change during the rehabilitation process. This is an important issue in giving prognostic information. We assume that expectations of the individual patient are based on prognostic information received from professionals and the progress that is

made so far, and are also influenced by subjective factors, such as understanding and coping. Predicting the functional outcome after SCI is most reliable if the expectations of both the professionals and the patients are taken into account.

Expectations of the individual patient are a complicated construct, but we believe that they should play an important role in goal-setting and involvement of patients in their rehabilitation process. Goal-setting forms the basis of interdisciplinary teamwork, which means that the whole team works towards goals relevant to the patient[8]. The results of rehabilitation interventions depend on the patients' expectations regarding functional outcome and the goals they want to attain. Especially in later phases of the rehabilitation programme the patient becomes more autonomous and responsible for achieving the goals, with the rehabilitation team acting as a coach. The team gradually loses the more paternalistic professional attitude, which is indispensable at the start of the rehabilitation programme. More research is needed to evaluate the process of interdisciplinary goal-setting and treatment on its effectiveness and efficiency.

The outcomes of independence in bladder and bowel care of our study population were poor. In order to reduce the practical and emotional consequences of incontinence, focus on optimal independence in bladder and bowel care is essential in the rehabilitation programme. An urologist and a nurse specialised in bladder and bowel problems are recommended as a full member of the rehabilitation team and they should also play an important role during long-term follow up.

Reintegration in work

The most important goal of rehabilitation is to enable disabled people to return to independent and satisfying lives in the community. This thesis evaluates the outcomes and process towards participation following SCI, in order to improve information to the patient, to enhance vocational rehabilitation and reintegration programmes and set out policies regarding work disablement. The rate of successful job reintegration was higher than expected from literature and the patient's expectations regarding future participation turned out to be an important indicator of the vocational outcome. Despite several useful job modifications, the unmet needs regarding reintegration interventions and negative experiences in the current job should not be neglected.

The study group is a representative cohort of patients with traumatic SCI with vocational potential in The Netherlands. All findings in this part of our research are based on the reports of the respondents, which makes them obviously subjective. Most parts of the questionnaire were standardised measures and used in other Dutch studies. We sent the questionnaire at least two years after the SCI, so that the respondents had their first definitive assessment of work disablement according to the Dutch Work Disability Act. The interval between the injury and the current assessment showed

considerable variation, which means that the level of experience with the reintegration process in time also varied within the study population.

From a social point of view return to work is regarded as one of the most important outcomes of reintegration in society. Despite the serious consequences of the SCI we conclude that a fatalistic attitude towards resumption of paid work is unfounded. The vocational outcomes of this study are encouraging. We have to take into account that until recently the economy was booming and the Dutch government stimulated work participation. Unlike several years ago, protection of income by social security is now secondary to being employed. Reintegration in work is a complex process that results from an interaction of many factors. In this study 45% of those who were employed pre-injury had positive expectations regarding work resumption and this was associated with a higher educational level. This study shows that the expectations of the patient are a strong indicator of success of reintegration in work. The role of the patient in predicting the vocational outcome is very important.

Because of physical disabilities as a consequence of SCI, job modifications are often indispensable to resume work. Material adaptations can compensate for reduced functional abilities and ambulation. Immaterial adjustments such as reduction of working hours and personal time management, make it possible to deal with the extra time needed for self-care and transport, and with reduced physical capacity. The majority of the workers undergo extensive changes in working hours. Financial consequences should be at least partially compensated by benefit from the Work Disability Act, which make it attractive to carry on working, both for the employer and for the employee.

Most of the working respondents changed to other jobs, especially if physically demanding jobs were concerned. As a consequence of legislation, employers are obliged to adjust the job or offer an alternative more suitable job. In view of tremendous changes in the first years following the SCI, it seems most comfortable for the person involved to return to the job and be spared the life-event of a new job. However, persons who changed to other jobs in this study are on average more satisfied with the job, experience less reduction of working hours, and are less dependent on benefits from the Work Disability Act. It confirms the assumption that new jobs are less physically demanding and match better with the disabilities. As persons who change to a different employer receive more vocational re-training and need more time to return to work, long-term counselling of this group is essential. Further prospective research is needed to find out in which situations the reintegration in a new job finally has more advantages.

In spite of several measures that should stimulate employers to keep disabled people employed, we know that the chances to resume work are restricted for patients with chronic diseases and disabilities[9-11]. Those who are motivated to resume work will find obstacles on their way. In this study both those who failed and those who succeeded in reintegrating, mentioned

several unmet needs. Negative experiences of persons with a paid job several years after the SCI, should not be neglected. To make reintegration in work successful on the long run, several interventions that fit personal requirements are indispensable. The rehabilitation team should play an important role.

Firstly, this study supports the importance of early interventions aiming at optimal participation, integrated in the rehabilitation process. The chance to have a paid job several years after the SCI is best for higher-educated people and for those who expect to return to their former jobs. Educational opportunities should be explored extensively for those who are motivated and potential candidates for vocational training should be indicated. Detailed information on these issues must be available. Besides, we advocate that the rehabilitation team plays an active role in drawing up a reintegration plan before discharge from the rehabilitation centre, supported by the patient, employer and all professionals involved in the reintegration process. This plan includes a description of the physical and mental abilities of the individual patient and inventory of required adaptations, set down by the rehabilitation team. The employer and the physician on occupational health give an indication of the requirements the job should meet. The employer is responsible for creating opportunities to resume work by adjusting the job or providing another job with less physical workload. The patient plays a central role and his expectations, wishes and needs regarding the reintegration are of great importance. A personal reintegration budget should be offered to overcome financial barriers. In recent years the concept of a vocational reintegration plan is laid down by law in the *Wet Verbetering Poortwachter,* an act that stimulates the employee and employer to start reintegration activities within six weeks. The effects of this act will become clear in the near future. We hope that the advantages of these tailor-made reintegration plans will prevail over the disadvantages of bureaucratic and lingering procedures.

Secondly, the support and interventions during the complex reintegration process should take place within the scope of the rehabilitation team. Coaching through the forest of rules and legislation is necessary to facilitate the process and keep the patient closely associated with his own reintegration process. A case manager who links the rehabilitation team and the work professionals and provides up-to-date information, can play an important role in this complex process of vocational reintegration.

Thirdly, during and also after the reintegration process the subjective experience of workers should not be neglected, especially when extensive changes in the job take place. The current experience and satisfaction of the working respondents in our study group were on average positive. Nevertheless, the negative experience associated with work, absence due to illness, and unmet needs regarding adjustments and support, are important signals that people with SCI are at risk of losing their jobs. This favours long-term follow-up by professionals, including those from the rehabilitation

team if necessary. It must be considered a challenge to complete the continuum of care for people with SCI with adequate vocational rehabilitation facilities.

In terms of future research, prospective studies are needed regarding the process of reintegration in society. Identification of subgroups of individuals who need special services or who experience problems in the reintegration process following SCI, might enhance the quality of individual counselling and effective interventions. Effect studies on the result of vocational reintegration programmes are an important next step.

Participation and satisfaction

Finally we discuss the outcomes of vocational and leisure participation in relation to life satisfaction, several years after the spinal cord injury. It is an important finding that a substantial number of people with SCI are able to retain a satisfying productive life in terms of paid work, or find other roles and activities to compensate for their lost jobs. The level of change in participation is not associated with the type and consequences of the SCI. As we expected, a lot more time is spent on self-care. Moreover, we think that the extra time that is needed for all inconveniences outdoors is usually underestimated.

Most respondents of our study are satisfied with their lives, which is often found in studies on the quality of life among persons with chronic diseases. After an intensive process of adjustment, a lot of people with serious disabilities are able to cope with their handicaps. The life satisfaction does not seem to be associated with being employed in the long run. It illustrates that most of the work-disabled people with a SCI gradually adjust to a situation without paid work. Persons who were not satisfied with their lives are particularly dissatisfied with their work and leisure situation, and report more unmet needs regarding support from professionals.

Participation issues deserve more priority during follow-up of the multidisciplinary rehabilitation team. For some patients it is too premature to focus on resumption of work and leisure during the rehabilitation period, due to a delayed or postponed coping and acceptance process. Also for those who fail to reintegrate in work a renewed attempt in creating leisure opportunities should be made, even if it is made several years after the initial rehabilitation period. In-depth interviews with all persons involved can reveal which interventions are best to promote satisfactory participation, and in which phase they are most effective.

Conclusions

The results of this study emphasise the need for a regional SCI-care system. Rehabilitation activities are integrated with this care system from the first day after the injury until the phase of long-term follow-up after reintegration into society. In this whole process personal experiences and unmet needs of

people with SCI are at the centre. The level of independence in daily activities after SCI is often lower than indicated by theoretical models. In the process of goal setting regarding future functioning, the assessment of expectations of the individual patient and the rehabilitation team should play an important role. This enhances functional prognosis and increases the involvement of the patient in the rehabilitation process.

People with SCI are able to achieve satisfactory participation levels. A majority of them reintegrate in paid work. Focus on the reintegration process should start during the inpatient rehabilitation period. An active role of the rehabilitation team is recommended in drawing up a reintegration plan in close collaboration with the patient and employer. Long-term follow-up by the rehabilitation team, in which attention is paid to vocational and leisure issues, completes the continuum of care for people with SCI.

References

1. DeVivo MJ, Kartus PL, Stover SL, Fine PR. Benefits of early admission to an organised spinal cord injury care system. Paraplegia 1990;28:545-555.
2. Oakes DD, Wilmot CB, Hall KM, Sherk JP. Benefits of early admission to a comprehensive trauma center for patients with spinal cord injury. Arch Phys Med Rehab 1990;71:637-643.
3. Yarkony GM, Roth EJ, Meyer PR, Lovell L, Heinemann AW, Betts HB. Spinal cord injury care system: fifteen year experience at the rehabilitation institute of Chicago. Paraplegia 1990;28: 321-329.
4. Post MWM, van Asbeck FWA, van Dijk AJ, Schrijvers AJP. Services for spinal cord injured: availability and satisfaction. Spinal Cord 1997;35:109-115
5. Post MWM, Witte LP de, Asbeck FWA van, Dijk AJ van, Schrijvers AJP. Predictors of health status and life satisfaction in spinal cord injury. Arch Phys Med Rehabil 1998;78:395-402.
6. Cox RJ, Amsters DI, Pershouse KJ. The need for a multidisciplinary outreach service for people with spinal cord injury living in the community. Clinical Rehabilitation 2001;15:600-606.
7. Mahoney FI, Barthel DW. Functional evaluation: the Barthel Index. A simple index of independence useful in scoring improvement in the rehabilitation of the chronically ill. Maryland Med J 1965;14:61-65.
8. Wade DT. Evidence relating to goal planning in rehabilitation. Clin Rehabil 1998;12:273-275.
9. Andries F, *et al*. Vocational perspectives and neuromuscular disorders. International Journal of Rehabilitation Research 1997;20:255-273.
10. Wevers CWJ, Brouwer OF, Padberg GW, Nijboer ID. Job perspectives in facioscapulohumeral muscular dystrophy. Disability and Rehabilitation 1993;15:24-28.
11. Schoppen T. Functional outcome after a lower limb amputation (thesis). University of Groningen, 2002.

Summary

Patients with spinal cord injuries (SCI) are confronted with motor and sensory deficits as well as bladder, bowel and sexual dysfunction, which lead to a fundamental change of life. Because of the extensive medical, emotional and social consequences of the SCI, multidisciplinary management is essential. All over the world rehabilitation programmes have been developed in order to enhance the functional outcome after SCI. Important goals of rehabilitation are maximising the independence in daily activities and providing optimal reintegration in society. This thesis focuses on the functional outcome after a spinal cord injury.

The functional outcome can be described according to the three levels of the International Classification of Functioning, Disability and Health (ICF), namely 1) functions and anatomical structures, 2) activities and 3) participation. Several frameworks were developed for considering subjective rehabilitation outcomes and interventions based on the ICF. They are an important source of inspiration for this thesis.

Knowledge of the functional outcome is indispensable to provide accurate prognostic information for the patient and family soon after the SCI. Moreover, it is essential to improve acute medical treatment and rehabilitation, to set out health care policies for the SCI disabled, and to evaluate the quality of care. Extensive research has been done on the outcomes of rehabilitation after SCI. Most studies have focused on incidence rates and general characteristics of people with SCI. Objective predictors and outcomes of self-care and work have been comprehensively analysed.

At the outset of our study little was known about the characteristics of patients with spinal cord lesions in The Netherlands. More knowledge was needed about the actual outcomes of activities and participation, and particularly of the results of vocational reintegration, as this largely takes place beyond the scope of the rehabilitation team. In literature the information on the process of rehabilitation and reintegration into society after SCI is limited. Our attention is drawn to the role of the individual patient during the rehabilitation process, and the personal experiences and satisfaction of people with SCI after the reintegration in society.

The main objectives of this thesis are:

1. To give an epidemiological overview of the characteristics of a cohort of patients with spinal cord lesions and their process of rehabilitation;
2. To describe the outcome of independence in daily activities of patients with spinal cord injuries at discharge from the rehabilitation centre, in relation to the early expectations of the rehabilitation team and the individual patient at admission;
3. To describe the outcomes of vocational and leisure participation several years after the spinal cord injury, in relation to the early expectations, reintegration interventions, the current experiences, satisfaction and unmet needs.

In the first part of this thesis an introduction on the subject is given (chapter 1), followed by an epidemiological description of the population with SCI (chapter 2).

Chapter 1 is the introduction and includes a review of the literature and the aims of this thesis. In *chapter 2* an overview is given of the characteristics of a cohort of patients with spinal cord lesions. It presents the occurrence of SCI in The Netherlands, the general characteristics and rehabilitation routing of this patient group. Data are gathered of 293 patients who followed a comprehensive inpatient rehabilitation programme.

In The Netherlands on average sixteen new cases per million per year were admitted to the rehabilitation centre, and this is comparable with the rates found in other European studies. Patients with non-traumatic lesions formed half of the rehabilitation population and are distinguished by age and sex. As it concerns on average older people this subgroup benefits from special programmes with realistic objectives.

Acute medical care is fragmented as patients come from many different hospitals and departments. Aiming at optimal rehabilitation management a regional SCI care system is recommended, based on close collaboration between a special SCI department in an academic or top-referent hospital and the rehabilitation centre. Nearly all patients go home after discharge. Attention paid to independent living programmes, appropriate housing facilities and more rapid procedures, can reduce the length of stay in the rehabilitation centre and enhance discharge to the patient's environment.

The second part of this thesis evaluates the functional outcome regarding daily activities in relation to the expectations. The objectives were to provide a more accurate prognosis of independence in daily activities for each type of SCI, and to enlarge the role of the patient in setting realistic rehabilitation goals. Results of independence in activities of daily living at discharge after inpatient rehabilitation were compared to the expected functional outcome based on theoretical models (chapter 3), and to the early expectations of the professionals

and the individual patient at admission (chapter 4). Data on expectations of the patient and rehabilitation team and functional progress were gathered from the database of the Rehabilitation Information System - Information System for patients with spinal cord injury (RIS-DIS). This information system was developed in the 1970s to evaluate the rehabilitation treatment of patients with SCI in The Netherlands and to work out a prognostic model for functional outcome. Data were obtained of 55 patients with traumatic SCI who followed a comprehensive inpatient rehabilitation programme.

In *chapter 3* the recovery of functional improvement during the inpatient rehabilitation period is evaluated and compared with information from other studies. Nearly all patients with complete spinal cord lesions at admission kept complete motor and sensory loss. Significant progress in independence was made in self-care, ambulation, and incontinence care. Differences in the extent of functional improvement were found between subgroups with different types of SCI. The level of independence after inpatient rehabilitation was not as good as expected, based on the theoretical models. This is an important issue in giving prognostic information. Particularly as far as bladder and bowel care are concerned, poor results were found. Attention paid to urological management regarding incontinence and optimal independence in incontinence care, was recommended as an important part of the rehabilitation programme.

In *chapter 4* the early expectations of the rehabilitation team and patients regarding functional outcome were explored and related to the results of independence after the inpatient rehabilitation programme. Prediction of functional outcome soon after the SCI is most successful if the expectations of the rehabilitation team and patients are combined. Prognosis of independence in self-care of patients with paraplegia and mobility potential of patients with a complete SCI, is usually clear at admission. However, early prediction of the outcome concerning self-care of patients with tetraplegia and mobility of patients with incomplete lesions is far more complicated. Gradual adjustment of objectives during the rehabilitation process is needed, in close collaboration between the professionals and the individual patient.

Although a satisfactory participation is one of the ultimate goals of rehabilitation, the process of reintegration in society takes largely place outside the scope of the rehabilitation centre. The third part of this thesis is about participation and reintegration in society. The aim of this part is to provide topical information about the outcomes of vocational and leisure participation following SCI as well as the reintegration interventions. Both the process of reintegration in work (chapter 5) and the experiences with the current job situation (chapter 6) were studied, and changes in participation after SCI were related to life satisfaction (chapter 7). Data are gathered from a mailed questionnaire about work and leisure activities, which was developed for this study. The questionnaire was returned by 57 persons with traumatic SCI (response 83%), aged 18 to 60 years, who earlier followed a rehabilitation programme.

In *chapter 5* the vocational reintegration process after SCI was studied. Of the 49 respondents who were employed at the moment of the SCI, 45% expected to resume work. Positive expectations were associated with higher education. Two-thirds returned to work, which was more than expected from literature. The chance to reintegrate successfully is significantly better for those patients who expect to return to their jobs. In this study several personal and injury-related variables proved not to be associated with success. A description is given of the reintegration interventions, including vocational re-training, changes in job type or working hours, and adaptations of the workplace. In view of the experiences and unmet needs, focus on the reintegration process should start during the rehabilitation period. A reintegration plan is advocated, drawn up by the rehabilitation team, in which all necessary steps and responsibilities of the patient, employer and reintegration professionals are recorded.

In *chapter 6* the experience with the current job situation is presented. It starts with an overview of the health status, disabilities and satisfaction per type of SCI. The number of work-related disabilities and perceived physical functioning are associated with the extent and not with the level of the lesion. There were no differences between subgroups with different types of SCI as far as being employed or general satisfaction were concerned. Of the respondents 60% were currently employed, which was related to a higher level of education. Persons who changed to a different employer needed more time to resume work than those who returned to their former jobs and employer, but they experienced less loss of working hours, less benefit from the Work Disability Act, and more job satisfaction. Despite the high level of job satisfaction of the workers, the reported negative job experiences and absence of work due to the SCI should not be neglected. This asks for long-term counselling of the SCI disabled during and after the reintegration period with more attention paid to their personal experiences and needs.

In *chapter 7* attention is paid to the changes in vocational and leisure participation and current satisfaction of people with SCI after reintegration in society. The number of hours spent on participation activities have changed to a great extent. This is mainly explained by a large reduction of working hours of more than 50%. Substantial variation is found in the degree of loss of participation. Part of the study group without paid work compensated the loss of work with domestic and leisure activities. The level of change in participation is not significantly associated with the number of work-related disabilities and SCI-specific health problems. As in many other studies concerning chronically disabled people, most persons with SCI are satisfied with the quality of their lives. The level of satisfaction is not significantly related to SCI-specific and participation-related variables. Reduced perceived quality of life is particularly associated with a unsatisfactory vocational and leisure situation and more unmet needs regarding reintegration interventions. Focus on work and leisure during

follow-up of the rehabilitation team several years after the SCI, might enhance a satisfactory participation.

In the general discussion the most important findings and weaknesses of this study are addressed, as well as the consequences and challenges for the rehabilitation medicine. Recommendations for further research are given. The results of this study emphasise the need for a regional SCI-care system. Rehabilitation activities are integrated with this care system from the first day after the injury until the phase of long-term follow-up after reintegration into society. In this whole process personal experiences and unmet needs of people with SCI are at the centre. The level of independence in daily activities after SCI is often lower than indicated by theoretical models. In the process of goal-setting regarding future functioning, the assessment of expectations of the individual patient and the rehabilitation team should play an important role. This enhances functional prognosis and increases the involvement of the patient in the rehabilitation process.

People with SCI are able to achieve satisfactory participation levels. A majority of them reintegrate in paid work. Focus on the reintegration process should start during the inpatient rehabilitation period. An active role of the rehabilitation team is recommended in drawing up a reintegration plan in close collaboration with the patient and employer. Long-term follow-up by the rehabilitation team, in which attention is paid to vocational and leisure issues, completes the continuum of care for people with SCI.

Samenvatting

Een dwarslaesie gaat gepaard met motorische en sensibele uitvalsverschijnselen, stoornissen van de blaas- en darmfunctie en gestoorde seksuele functies, die leiden tot een fundamentele verandering van het leven van de betrokkene. Vanwege de uitgebreide medische, emotionele en sociale gevolgen van een dwarslaesie is een multidisciplinaire behandeling noodzakelijk. Over de hele wereld zijn revalidatieprogramma's ontwikkeld, gericht op het optimaliseren van het functioneren. De belangrijkste doelen van de revalidatie zijn het bevorderen van de zelfstandigheid in dagelijkse activiteiten en het zorgen voor een goede reïntegratie in de maatschappij. Dit proefschrift gaat over het functioneren met een dwarslaesie.

Middels de *International Classification of Functioning, Disability and Health (ICF)* kan het menselijk functioneren worden beschreven op drie niveaus, te weten 1) lichaamsfuncties en anatomische structuren, 2) activiteiten en 3) participatie. Ter classificatie van subjectieve revalidatie-uitkomsten en revalidatie-interventies zijn diverse modellen ontwikkeld die gebaseerd zijn op de ICF. Deze vormen een belangrijke inspiratiebron voor dit proefschrift.

Kennis van de *functional outcome* is nodig om de patiënt en zijn sociale omgeving na een dwarslaesie goed te kunnen informeren over de prognose. Bovendien is het belangrijk om de acute opvang en revalidatie te verbeteren, beleid te kunnen maken gericht op zorg voor mensen met een dwarslaesie en de kwaliteit van zorg te kunnen toetsen. Naar de revalidatie-uitkomsten na een dwarslaesie is al veel wetenschappelijk onderzoek gedaan. De meeste studies richten zich op incidentie en specifieke kenmerken van mensen met een dwarslaesie. Predictoren en resultaten van het functioneren op het gebied van zelfverzorging en werk zijn uitgebreid bestudeerd.

Aan het begin van dit onderzoek was er weinig bekend over de kenmerken van mensen met een dwarslaesie in Nederland. Er was meer kennis nodig van actuele uitkomsten op het gebied van activiteiten en participatie, en met name ook van de resultaten van arbeidsreïntegratie, aangezien zich dat grotendeels afspeelt buiten het gezichtsveld van de revalidatie. Informatie over het proces van revalidatie en reïntegratie in de samenleving is slechts beperkt in de literatuur aanwezig. Onze aandacht gaat met name uit naar de rol van de individuele patiënt in het revalidatieproces

en de persoonlijke ervaringen en tevredenheid van mensen met een dwarslaesie na terugkeer in de maatschappij.

De doelstellingen van dit proefschrift zijn:

1. Het geven van een epidemiologisch overzicht van de kenmerken van een groep patiënten met een dwarslaesie en hun revalidatieproces.
2. Het beschrijven van de resultaten van zelfstandigheid in dagelijkse activiteiten van patiënten met een dwarslaesie bij ontslag uit het revalidatiecentrum in relatie tot eerdere verwachtingen van het revalidatieteam en de individuele patiënt.
3. Het beschrijven van de resultaten van arbeidsparticipatie en vrijetijdsbesteding enkele jaren na het ontstaan van de dwarslaesie, in relatie tot de eerdere verwachtingen, reïntegratie-interventies, de huidige ervaringen, tevredenheid en behoeften.

Het eerste deel van dit proefschrift betreft een introductie over het onderwerp (hoofdstuk 1), gevolgd door een epidemiologische beschrijving van de studiepopulatie (hoofdstuk 2).

Hoofdstuk 1 beschrijft een literatuuroverzicht over het functioneren met een dwarslaesie en de doelen van dit proefschrift. In h*oofdstuk 2* wordt een overzicht gegeven van de karakteristieken van een cohort patiënten met een dwarslaesie. Het richt zich op het voorkomen van dwarslaesies in Nederland en specifieke kenmerken van deze patiëntengroep. Bovendien worden ook aspecten van het revalidatietraject na een dwarslaesie in kaart gebracht. Er zijn gegevens verzameld van 293 patiënten die een klinisch revalidatieprogramma hebben gevolgd.

In Nederland worden gemiddeld 16 nieuwe patiënten per miljoen inwoners per jaar naar het revalidatiecentrum verwezen en dat is vergelijkbaar met de cijfers in andere Europese studies. Patiënten met niet-traumatische dwarslaesies vormen de helft van de revalidatiepopulatie en onderscheiden zich door leeftijd en geslacht. Aangezien het veel ouderen betreft is deze subgroep gebaat bij een aangepast revalidatieprogramma met realistische doelen.

De acute zorg is gefragmenteerd, zoals blijkt uit het feit dat patiënten worden verwezen vanuit veel verschillende ziekenhuizen en afdelingen. Voor een optimaal revalidatiebeleid wordt een regionale dwarslaesiezorg-keten aanbevolen, uitgaande van een nauwe samenwerking tussen een academisch of topklinisch ziekenhuis en het revalidatiecentrum. Nagenoeg alle patiënten worden uiteindelijk naar huis ontslagen. Aandacht voor programma's gericht op zelfstandig wonen, adequate woonvoorzieningen en snellere procedures kunnen de opnameduur in het revalidatiecentrum bekorten en ontslag naar de eigen woonomgeving bevorderen.

Het tweede deel van het proefschrift evalueert het functioneren in dagelijkse activiteiten in relatie tot de verwachtingen hieromtrent. Deze deelstudie beoogt het stellen van een meer nauwkeurige prognose van zelfstandigheid in activiteiten van het dagelijks leven (ADL) per dwarslaesietype, en het vergroten van de rol van de patiënt in het vaststellen van realistische revalidatiedoelen. De behaalde ADL-zelfstandigheid bij ontslag uit de klinische revalidatie werd vergeleken met het verwachte functioneren op grond van theoretische modellen (hoofdstuk 3), en met de verwachtingen van de behandelaars en de individuele patiënt aan het begin van de revalidatieopname (hoofdstuk 4). Gegevens van de verwachtingen van de patiënt en het revalidatieteam bij opname, en de functionele vorderingen tijdens de revalidatie zijn verzameld uit de database van het Revalidatie Informatie Systeem – Dwarslaesie Informatie Systeem (RIS-DIS). Dit informatiesysteem werd in de jaren zeventiger in Nederland ontwikkeld om de revalidatiebehandeling van patiënten met een dwarslaesie te evalueren en te komen tot een prognostisch model betreffende hun functioneren. Geanonimiseerde gegevens zijn verzameld van 55 patiënten met een traumatische dwarslaesie die een klinisch revalidatieprogramma hebben doorlopen.

In *hoofdstuk 3* wordt het herstel van stoornissen en functionele vaardigheden gedurende de klinische revalidatieperiode bestudeerd en vergeleken met de resultaten van andere studies. Nagenoeg alle patiënten met een complete dwarslaesie bij opname behielden volledige neurologische uitval. Significante vooruitgang in zelfstandigheid vond plaats ten aanzien van persoonlijke verzorging, mobiliteit en incontinentiezorg. Er werden verschillen gevonden in de mate van functionele verbetering tussen subgroepen met verschillende dwarslaesietypen. De mate van zelfstandigheid aan het einde van de klinische revalidatie blijkt niet zo goed te zijn als verwacht op grond van theoretische modellen in de literatuur. Dit is een belangrijk punt in het geven van prognostische informatie. Er werden vooral zwakke resultaten gevonden met betrekking tot de blaas- en darmverzorging. Aandacht voor preventie van incontinentie en optimale zelfstandigheid in incontinentiezorg wordt aanbevolen als een belangrijk onderdeel van de revalidatie.

In *hoofdstuk 4* worden de verwachtingen van de patiënt en het revalidatieteam ten aanzien van het toekomstig functioneren onderzocht en gerelateerd aan de mate van zelfstandigheid na het klinische revalidatieprogramma. Het voorspellen van het functionele resultaat na een dwarslaesie was het meest succesvol als de verwachtingen van de patiënt en het revalidatieteam werden gecombineerd. De prognose van zelfstandigheid in zelfverzorging van patiënten met een paraplegie en mobiliteit van patiënten met een complete dwarslaesie zijn doorgaans duidelijk bij aanvang van de behandeling. Het vroeg voorspellen van uitkomsten ten aanzien van persoonlijke verzorging bij patiënten met een tetraplegie en mobiliteit bij patiënten met een incomplete laesie is veel gecompliceerder. Geleidelijke

aanpassing van de revalidatiedoelen gedurende het revalidatieproces is noodzakelijk in nauwe samenwerking tussen de patiënt en het behandelteam.

Hoewel een bevredigende participatie een van de hoogste doelen van de revalidatie is, speelt het proces van reïntegratie in de maatschappij zich grotendeels buiten het revalidatiecentrum af. Het derde deel van dit proefschrift gaat over participatie en reïntegratie in werk. Het doel van deze deelstudie is het geven van actuele informatie over uitkomsten op het gebied van arbeidsparticipatie en vrijetijdsbesteding, alsmede de gebruikte reïntegratie-interventies. Zowel het proces van reïntegratie in werk (hoofdstuk 5) als de ervaringen met de huidige arbeidssituatie (hoofdstuk 6) zijn bestudeerd. Daarnaast zijn de veranderingen in participatie na de dwarslaesie gerelateerd aan de mate van tevredenheid (hoofdstuk 7). De gegevens zijn afkomstig uit een vragenlijst over werk en vrijetijdsbesteding die gemaakt is voor deze studie. Hierbij is gebruik gemaakt van de vragenlijst Arbeidshandicap van TNO Arbeid. De vragenlijst werd teruggestuurd door 57 personen met een traumatische dwarslaesie van 18 tot 60 jaar, die eerder een revalidatieprogramma hebben gevolgd. De respons was 83 procent.

Hoofdstuk 5 richt zich op het proces van arbeidsreïntegratie na een dwarslaesie. Van de 49 respondenten die voor het ongeval werkten, verwachtte bijna de helft het werk te kunnen hervatten. Een positieve verwachting ten aanzien van terugkeer naar werk was gerelateerd aan een betere opleiding. Tweederde heeft het werk hervat en dat is meer dan op grond van de literatuur was verwacht. De kans om succesvol te reïntegreren is significant groter voor mensen met positieve verwachtingen ten aanzien van werk. Verschillende persoonlijke en dwarslaesiegerelateerde factoren bleken niet van invloed op het succes van de reïntegratie. Diverse ervaringen met het reïntegratieproces zijn gerapporteerd, inclusief de arbeidsrevalidatie en omscholing, de veranderingen in het soort werk en arbeidsuren, en de werkaanpassingen. Op basis van de resultaten luidt het advies om begeleiding bij de arbeidsreïntegratie al tijdens de revalidatiefase te starten. Het lijkt heel zinvol dat het revalidatieteam een belangrijke rol speelt bij het opstellen van het reïntegratieplan. Hierin kunnen alle benodigde stappen en verantwoordelijkheden van de patiënt, werkgever, reïntegratieprofessionals en het revalidatieteam worden vastgelegd.

Hoofdstuk 6 gaat over de ervaringen met de huidige werksituatie. Eerst wordt een overzicht gegeven van de gezondheidstoestand, de beperkingen en tevredenheid van de respondenten per dwarslaesietype. Het aantal werkgerelateerde beperkingen en het ervaren fysiek functioneren blijkt geassocieerd te zijn met de mate van compleetheid van de dwarslaesie en niet met de laesiehoogte. Er is geen verschil per dwarslaesietype wat betreft het hebben van een betaalde baan en de algehele tevredenheid. Van degenen die voorheen werkten heeft 60% nu een betaalde baan en zij zijn gemiddeld hoger opgeleid. Degenen die werkzaam zijn bij een nieuwe werkgever hadden meer tijd nodig voor hun reïntegratie dan degenen die terugkeerden

naar hun oude werkgever, maar ook een beperktere reductie van het aantal arbeidsuren, minder afhankelijkheid van een WAO (Wet op de Arbeidsongeschiktheidsverzekering)-uitkering en meer tevredenheid met het werk. Ondanks een hoge arbeidssatisfactie van de werkenden moeten de negatieve werkervaringen en het ziekteverzuim als gevolg van de dwarslaesie niet worden onderschat. Dit pleit voor een langdurige begeleiding van mensen met een dwarslaesie tijdens en na de reïntegratieperiode met meer aandacht voor hun persoonlijke ervaringen en behoeften.

In *hoofdstuk 7* wordt aandacht besteed aan de veranderingen in arbeidsparticipatie en vrijetijdsbesteding en de mate van tevredenheid van mensen met een dwarslaesie na de reïntegratie in de maatschappij. Het aantal uren dat besteed wordt aan participatieactiviteiten is erg veranderd. Dat is vooral toe te schrijven aan de forse vermindering van het aantal arbeidsuren met meer dan de helft. Er is een grote variatie in de mate van verlies aan participatie. Een gedeelte van de onderzoeksgroep compenseert het verlies van werk met huishoudelijke en hobbyactiviteiten. Er blijkt geen relatie te bestaan met het aantal werkgerelateerde beperkingen en dwarslaesiespecifieke gezondheidsproblemen. Net als in veel andere studies over mensen met chronische aandoeningen zijn de meeste mensen met een dwarslaesie tevreden met de kwaliteit van hun leven. De mate van tevredenheid is niet gecorreleerd aan dwarslaesiespecifieke of participatiegerelateerde variabelen. Een verminderde ervaren kwaliteit van leven blijkt vooral samen te hangen met ontevredenheid over de huidige werksituatie en vrijetijdsbesteding. De ontevreden groep heeft meer behoefte aan contacten met professionals. Aandacht voor werk en alternatieve dagbesteding door het revalidatieteam lijkt ook op langere termijn na een dwarslaesie uitermate zinvol ter bevordering van een bevredigende participatie.

In de algemene discussie zijn de belangrijkste conclusies geformuleerd en wordt ingegaan op de consequenties en uitdagingen voor de revalidatiegeneeskunde. Tevens worden aanbevelingen voor vervolgonderzoek gedaan. De resultaten van het onderzoek onderstrepen het belang van een regionale zorgketen. Hierin zijn de revalidatieactiviteiten geïntegreerd vanaf de eerste dag na het ontstaan van de dwarslaesie tot in de follow-upfase na reïntegratie in de samenleving. Gedurende dit hele proces staan de persoonlijke ervaringen en behoeften van de patiënt centraal.

Het niveau van zelfstandigheid dat tijdens de klinische revalidatie wordt behaald blijkt vaak minder hoog te zijn dan op grond van theoretische modellen zou mogen worden verwacht. Bij het vaststellen van revalidatiedoelen dienen de verwachtingen van de patiënt en het revalidatieteam ten aanzien van het toekomstig functioneren een belangrijke rol spelen. Zij dragen bij aan een realistische functionele prognose en bevorderen bovendien de betrokkenheid van de patiënt bij het revalidatieproces.

Mensen met een dwarslaesie zijn in staat om naar tevredenheid deel te nemen aan het maatschappelijk leven. Een meerderheid reïntegreert naar

betaald werk. Idealiter start begeleiding bij de arbeidsreïntegratie al tijdens de klinische revalidatiefase, waarbij het revalidatieteam een belangrijke rol kan spelen in het opstellen van een reïntegratieplan in nauwe samenwerking met de patiënt en de werkgever. Follow-up door het revalidatieteam, waarin ook aandacht is voor de werksituatie en vrijetijdsbesteding, maakt de ketenzorg voor mensen met een dwarslaesie compleet.

Northern Centre for Healthcare Research (NCH) and previous dissertations

The Northern Centre for Healthcare Research (NCH) was founded in 1986 as a research institute of the University of Groningen (RUG), The Netherlands. Researchers from both the Medical and Social Faculty, with various professional backgrounds, are members of the NCH. These include medical sociologists, medical doctors, psychologists and human movement scientists. Research of the NCH is aimed at optimising quality of life of patients and quality of healthcare, and focuses on (a) determinants of health and illness, (b) consequences of illness, (c) the effects of medical treatment and decision making, and (d) the evaluation of health services and various types of interventions. At the time that this thesis is published, the NCH comprises five research programs.

Until 1998, the NCH covered two research programs, i.e. 'Determinants of Health' and 'Medical Decision Making and Evaluation of Healthcare'. The first program was reformulated in 1996 and was continued as 'Disorder, Disability and Quality of Life' (DDQ). Hence, previous dissertations in this area are listed as part of the present DDQ-programme. The second program was subdivided in 1998 into two new programs, i.e. 'Public Health and Public Health Services Research' and 'Rational Drug Use'. Dissertations published earlier within the second program are listed retrospectively under these new headings. In 1998, two new programs, 'Rehabilitation Programs Research' and 'Research in Motor Behaviour', were formulated and officially integrated in the NCH in January 1999. The accomplished dissertations since the start of the programs in 1998 are included in the list. In 2000 the Department of General Practice joined the NCH and together with the Rational Drug Use group initiated a new research program, i.e. 'Research in Evidence Based Medicine'.

More information regarding the institute and its research can be obtained from our internet site: *http://coo.med.rug.nl/nch*.

Disorder, Disability and Quality of Life

Stiegelis HE (2003) *A life less ordinary; cognitive adaptation and psychological functioning among cancer patients treated with radiotherapy.*
PROMOTORES: prof dr R Sanderman, prof dr AP Buunk. CO-PROMOTOR: dr M Hagedoorn

Heuvel ETP van den (2002) *Supporting caregivers of stroke patients; an intervention study.*
PROMOTORES : prof dr B Meyboom-de Jong, prof dr R Sanderman. CO-PROMOTOR: dr LP de Witte. REFERENT: dr LM Schure

Schroevers MJ (2002) *Short- and long-term adaptation to cancer; a comparison of patients with the general population.*
PROMOTOR: prof dr R Sanderman. REFERENT: dr AV Ranchor

Hoekstra-Weebers JEHM (2000) *Parental adaptation to pediatric cancer.*
PROMOTORES: prof dr EC Klip, prof dr WA Kamps. REFERENT: dr JPC Jaspers

Doeglas DM (2000) *Functional ability, social support and quality of life: a longitudinal study in patients with early rheumatoid arthritis.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr R Sanderman. CO-PROMOTOR: dr ThPBM Suurmeijer

Nijboer C (2000) *Caregiving to patients with colorectal cancer: a longitudinal study on caregiving by partners.* PROMOTORES: prof dr GAM van den Bos, prof dr R Sanderman. CO-PROMOTOR: dr AHM Triemstra

Tiesinga LJ (1999) *Fatigue and Exertion Fatigue: from description through validation to application of the Dutch Fatigue Scale (DUFS) and the Dutch Exertion Fatigue Scale (DEFS).*
PROMOTORES: prof dr WJA van den Heuvel, prof dr ThWN Dassen. CO-PROMOTOR: dr RJG Halfens

Jong GM de (1999*) Stress, stress management and issues regarding implementation*. PROMOTORES: prof dr PMG Emmelkamp, prof dr JL Peschar. REFERENT: dr R Sanderman

Alberts JF (1998*) The professionalized patient: sociocultural determinants of health services utilization.*
PROMOTOR: prof dr WJA van den Heuvel. REFERENT: dr R Sanderman

Eijk LM van (1997) *Activity and well-being in the elderly.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr SM Lindenberg. REFERENT: dr GIJM Kempen

Nieboer AP (1997) *Life-events and well-being: a prospective study on changes in well-being of elderly people due to a serious illness event or death of the spouse.*
PROMOTORES: prof dr SM Lindenberg, prof dr J Ormel

Scaf-Klomp W (1997) *Screening for breast cancer: attendance and psychological consequences.*
PROMOTOR: prof dr WJA van den Heuvel. REFERENT: dr R Sanderman

Zwanikken CP (1997) *Multiple sclerose: epidemiologie en kwaliteit van leven.*
PROMOTOR: prof dr J Minderhoud. CO-PROMOTORES: dr JW Groothoff, dr ThPBM Suurmeijer

Kooiker SE (1996) *Illness in everyday life: a health diary study of common symptoms and their consequences.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr J van der Zee

Krol B (1996) *Quality of life in rheumatoid arthritis patients: the relation between personality, social support and depression.*
PROMOTOR: prof dr WJA van den Heuvel. REFERENTEN: dr R Sanderman, dr ThPBM Suurmeijer

Ruiter JH de (1995) *Sociale ondersteuning en kwaliteit van leven bij patiënten met kanker.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr H Schraffordt Koops.
REFERENTEN: dr FLP van Sonderen, dr R Sanderman

Steverink N (1995) *Zo lang mogelijk zelfstandig: naar een verklaring van verschillen ten aanzien van opname in een verzorgingstehuis onder fysiek kwetsbare ouderen.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr TAB Snijders, prof dr J Ormel

Uitenbroek DG (1995) *Exercise behaviour*.
PROMOTOR: prof dr WJA van den Heuvel

Linden-van den Heuvell GFEC van (1994) *Voorbereiding op medische ingrepen.*
PROMOTOR: prof dr EC Klip

Linschoten CP van (1994) *Gezondheidsbeleving van ouderen: een Iongitudinale studie.*
PROMOTOR: prof dr WJA van den Heuvel. CO-PROMOTOR: dr J Ormel

Oosterhuis A (1994) *De gedragstherapeutische behandeling van slaapklachten.*
PROMOTOR: prof dr EC Klip

Ranchor AV (1994) *Social class, psychosocial factors and disease: from description towards explanation.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr AP Buunk.
REFERENTEN: dr R Sanderman, dr J Bouma

Reitsma B (1994) *The end of the line? Evaluation of a multidisciplinary team approach to chronic pain.*

PROMOTORES: prof dr EC Klip, prof dr JWF Beks, prof dr JP Hennis

Gerritsen JC (1993) *Onafhankelijkheid van ouderen: mogelijkheden en voorwaarden.*
PROMOTOR: prof dr WJA van den Heuvel

Heyink JW (1992) *Levertransplantatie: psycho-sociale aspecten.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr MJH Slooff.
REFERENT: dr Tj Tijmstra

Sonderen FLP van (1991) *Het meten van sociale steun.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr FN Stokman.
REFERENT: dr J Ormel

Kempen GIJM (1990) *Thuiszorg voor ouderen: een onderzoek naar de individuele determinanten van het gebruik van wijkverpleging en/of gezinsverzorging op verzorgend en huishoudelijk gebied.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr W Molenaar.
REFERENT: dr ThPBM Suurmeijer

Sanderman R (1988) *Life events, mediating variables and psychological distress: a longitudinal study.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr PE Boeke, prof dr PMG Emmelkamp.
REFERENT: dr J Ormel

Public Health and Public Health Services Research

Lege W de (2002) *Medische consumptie in de huisartspraktijk op Urk.*
PROMOTORES: prof dr D Post, prof dr JW Groothoff

Hoekstra EJ (2002) *Arbeidsbemiddeling met behulp van Supported Employment als interventie bij de reïntegratie van chronisch zieken; de rol van de arbeidsbemiddelaar, chronisch zieke en werkgever.*
PROMOTORES: prof dr JW Groothoff, prof dr K Sanders, prof dr WJA van den Heuvel, prof dr D Post

Enk JG van (2002) *Determinants of use of healthcare services in childhood.*
PROMOTORES: prof dr D Post, prof dr AJP Veerman, prof dr WJA van den Heuvel

Gecková A (2002) *Inequality in health among Slovak adolescents.*
PROMOTORES: prof dr D Post, prof dr JW Groothoff.
REFERENT: dr JP van Dijk

Dijk JP van (2001) *Gemeentelijk gezondheidsbeleid; omvang en doelgerichtheid.*
PROMOTORES: prof dr D Post, prof dr M Herweijer, prof dr JW Groothoff

Middel LJ (2001) *Assessment of change in clinical evaluation.*

PROMOTOR: prof dr WJA van den Heuvel. REFERENT: dr MJL de Jongste

Bijsterveld HJ (2001) *Het ouderenperspectief op thuiszorg; wensen en behoeften van ouderen ten aanzien van de thuis(zorg)situatie in Friesland*
PROMOTORES: prof dr D Post, prof dr B Meyboom-de Jong. REFERENT: dr J Greidanus

Dijkstra GJ (2001) *De indicatiestelling voor verzorgingshuizen en verpleeghuizen.*
PROMOTORES: prof dr D Post, prof dr JW Groothoff

Dalen IV van (2001) *Second opinions in orhopaedic surgery: extent, motives, and consequences.*
PROMOTORES: prof dr JR van Horn, prof dr PP Groenewegen, prof dr JW Groothoff

Beltman H (2001) *Buigen of barsten? Hoofdstukken uit de geschiedenis van de zorg aan mensen met een verstandelijke handicap in Nederland 1945-2000.*
PROMOTORES: prof dr D Post, prof dr AThG van Gennep

Pal TM (2001) *Humidifiers disease in synthetic fiber plants: an occupational health study.*
PROMOTORES: prof dr JGR de Monchy, prof dr D Post, prof dr JW Groothoff

Goossen WTF (2000) *Towards strategic use of nursing information in the Netherlands.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr ThWN Dassen, prof dr ir A Hasman

Hospers JJ (1999) *Allergy and airway hyperresponsiveness: risk factors for mortality.*
PROMOTORES: prof dr D Post, prof dr DS Postma, prof dr ST Weiss

Wijk P van der (1999) *Economics: Charon of Medicine?*
PROMOTORES: prof dr WJA van den Heuvel, prof dr L Koopmans, prof dr FFH Rutten.
REFERENT: dr J Bouma

Dijkstra A (1998) *Care dependency: an assessment instrument for use in long-term care facilities.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr ThWN Dassen

Tuinstra J (1998) *Health in adolescence: an empirical study of social inequality in health, health risk behaviour and decision making styles.*
PROMOTORES: prof dr D Post, prof dr WJA van den Heuvel. CO-PROMOTOR: dr JW Groothoff

Mink van der Molen AB (1997) *Carpale letsels: onderzoek naar de verzuimaspecten ten gevolge van*

carpale letsels in Nederland 1990-1993.
PROMOTORES: prof dr PH Robinson, prof WH Eisma. CO-PROMOTOR: dr JW Groothoff. REFERENT: dr GJP Visser

Mulder HC (1996) *Het medisch kunnen: technieken, keuze en zeggenschap in de moderne geneeskunde.*
PROMOTOR: prof dr WJA van den Heuvel

Dekker GF (1995) *Rugklachten-management-programma bij de Nederlandse Aardolie Maatschappij B.V.: ontwerp, uitvoering en evaluatie.*
PROMOTORES: prof dr D Post, prof WH Eisma. CO-PROMOTOR: dr JW Groothoff

Puttiger PHJ (1994) *De medische keuring bij gebruik van persluchtmaskers.*
PROMOTORES: prof dr D Post,prof dr WJA Goedhard. CO-PROMOTOR: dr JW Groothoff

Engelsman C & Geertsma A (1994) *De kwaliteit van verwijzingen.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr FM Haaijer-Ruskamp, prof dr B Meyboom-de Jong

Lucht F van der (1992) *Sociale ongelijkheid en gezondheid bij kinderen.*
PROMOTOR : prof dr WJA van den Heuvel. REFERENT: dr JW Groothoff

Research in Evidence Based Medicine

Pont LG (2002) *Assessing the quality of prescribing in general practice.*
PROMOTORES: prof dr FM Haaijer-Ruskamp, prof dr WH van Gilst, prof dr T van der Molen

Bemelmans WJE (2001) *Prevention of coronary heart disease by nutritional interventions. Impact of nutritional education in groups and supplementation with alpha-linolenic acid.*
PROMOTOR: prof dr B Meyboom-de Jong. CO-PROMOTOR: dr JF May. REFERENTEN: dr J Broer, dr EJM Feskens, dr FW Siero, dr AJ Smit

Veninga CCM (2000) *Improving prescribing in general practice.*
PROMOTOR: prof dr FM Haaijer-Ruskamp. REFERENT: dr P Denig

Veehof LJG (1999) *Polypharmacy in the elderly.*
PROMOTORES: prof dr B Meyboom-de Jong, prof dr FM Haaijer-Ruskamp

Vries SO de (1998) *Management strategies for intermittent claudication.*
PROMOTOR: prof dr MGM Hunink. REFERENT: dr JB Wong

Bosch JL (1997) *Outcome assessment of the percutaneous treatment of lilac artery occlusive disease.*
PROMOTORES: prof dr MGM Hunink, prof dr WPThM Mall, prof dr L Koopmans

Dijkers FW (1997) *Repeat prescriptions: a study in general practice in the Netherlands.*
PROMOTORES: prof dr B Meyboom-de Jong, prof dr FM Haaijer-Ruskamp, prof dr AF Casparie

Trigt AM van (1995) *Making news about medicines.*
PROMOTORES: prof dr TFJ Tromp, prof dr FM Haaijer-Ruskamp

Boerkamp E (1995) *Assessing professional services quality: an application in health care.*
PROMOTORES: prof dr JC Reuijl, prof dr FM Haaijer-Ruskamp

Denig P (1994) *Drug choice in medical practice: rationals, routines, and remedies.*
PROMOTORES: prof dr FM Haaijer-Ruskamp, prof dr H Wesseling

Jong-van den Berg LTW de (1992) *Drug utilization studies in pregnancy: what can they contribute to safety assessment?*
PROMOTORES: prof dr MNG Dukes, prof dr H Wesseling.
REFERENT: dr FM Haaijer-Ruskamp

Zijlstra IF (1991) *De regionaal klinisch farmacoloog.*
PROMOTORES: prof dr H Wesseling, prof dr FWJ Gribnau, prof dr C van Weel.
REFERENTEN: dr FM Haaijer-Ruskamp, dr H Wollersheim

Rehabilitation Programs Research (from 1998 onwards)

Sturms LM (2003) *Pediatric traffic injuries; consequences for the child and the parents.*
PROMOTORES: prof dr WH Eisma, prof dr HJ ten Duis, prof dr JW Groothoff. CO-PROMOTOR: dr CK van der Sluis

Meijer JWM (2002) *The diabetic foot syndrome; diagnosis and consequences.*
PROMOTORES: prof WH Eisma, prof dr JW Groothoff. CO-PROMOTORES: dr TP Links, dr AJ Smit

Schoppen T (2002) *Functional outcome after a lower limb amputation.*
PROMOTORES: prof WH Eisma, prof dr JW Groothoff, prof dr LNH Göeken. REFERENTEN: dr AM Boonstra, dr J de Vries

Rommers GM (2000) *The elderly amputee: rehabilitation and functional outcome.*
PROMOTOR: prof WH Eisma. CO-PROMOTOR: dr JW Groothoff

Halbertsma JPK (1999) *Short hamstrings & stretching: a study of muscle elasticity.*
PROMOTORES: prof WH Eisma, prof dr LNH Göeken. CO-PROMOTOR: dr JW Groothoff. REFERENT: dr ir AL Hof

Geertzen JHB (1998) *Reflex sympathetic dystrophy: a study in the perspective of rehabilitation medicine.*

PROMOTORES: prof WH Eisma, prof dr HJ ten Duis. CO-PROMOTOR: dr JW Groothoff.
REFERENT: dr PU Dijkstra

Sluis CK van der (1998) *Outcomes of major trauma.*
PROMOTORES: prof dr HJ ten Duis, prof WH Eisma

Research in Motor Behaviour (from 1998 onwards)

Kamsma YPT (2002) *Functional Reorganisation of basic motor actions in Parkinson's disease. Problem analysis, development and evaluation of a compensatory strategy training.*
PROMOTORES: prof dr P Rispens, prof dr WH Brouwer

Stevens M (2001) *Groningen Active Living Model (GALM): development and initial validation.*
PROMOTOR: prof dr P Rispens. REFERENTEN: dr KAPM Lemmink, dr MHG de Greef

Lettinga AT (2000) *Diversity in neurological physiotherapy: a comparative analysis of clinical and scientific practices.*
PROMOTORES: prof dr P Rispens, prof dr PJM Helders, prof dr A Mol

Heuvelen MJG van (1999) *Physical activity, physical fitness and disability in older persons.*
PROMOTOR: prof dr P Rispens. CO-PROMOTORES: dr WH Brouwer, dr GIJM Kempen.
REFERENT: dr MHG de Greef

Berkhuysen MA (1999) *Toward tailor-made cardiac rehabilitation: getting at the heart of the matters.*
PROMOTORES: prof dr AP Buunk, prof dr P Rispens.
REFERENT: dr R Sanderman

Curriculum Vitae

Marleen Schönherr werd op 14 juni 1966 geboren in Nijmegen. Van 1969 tot 1971 woonde zij in Aberdeen, Schotland. Na de lagere school doorliep zij het Gymnasium B aan het Titus Brandsma Lyceum in Oss. Van 1984 tot 1991 studeerde zij Geneeskunde aan de Rijksuniversiteit Limburg. In 1990 deed zij keuzestages bij W.G.M. Bakx, revalidatiearts in Revalidatiecentrum Hoensbroeck, en bij J.D. Martina, revalidatiearts in het Mgr. Verriet Instituut op Curaçao. Na haar basisartsexamen werkte zij een jaar als assistent geneeskundige niet in opleiding (AGNIO) Interne Geneeskunde in het Willem Alexanderziekenhuis in ’s Hertogenbosch. Daarna was zij AGNIO Revalidatiegeneeskunde in de Sint Maartenskliniek te Nijmegen. Van 1992 tot 1996 deed zij haar opleiding tot revalidatiearts in het Opleidingscomplex Revalidatiegeneeskunde Groningen met professor W.H. Eisma als opleider. Van 1997 tot 2002 was zij werkzaam als revalidatiearts en staflid van het Martini Ziekenhuis Groningen. Vanaf 1997 werkt zij in het Revalidatiecentrum Beatrixoord te Haren, inmiddels Centrum voor Revalidatie lokatie Beatrixoord van het Academisch Ziekenhuis Groningen.

Stellingen

behorende bij het proefschrift

Functional Outcome after Spinal Cord Injury: Activities and Participation

1. Kennis van de persoonlijke verwachtingen van de patiënt met een dwarslaesie is onmisbaar bij het stellen van een realistische functionele prognose. (dit proefschrift).

2. Het vaststellen van revalidatiedoelen met betrekking tot “lopen” na een dwarslaesie, is alleen zinvol als de patiënt en het revalidatieteam een eenduidige definitie van dit begrip hanteren. (dit proefschrift)

3. Ten behoeve van optimale sociale onafhankelijkheid dient het revalidatieteam mede te bestaan uit een uroloog en incontinentieverpleegkundige. (dit proefschrift)

4. Aandacht voor werk en andere dagbesteding verdient prioriteit om de tevredenheid over de kwaliteit van leven na een dwarslaesie te verhogen. (dit proefschrift)

5. Ondanks de ernstige gevolgen van een dwarslaesie is een fatalistische houding ten aanzien van werkhervatting niet gefundeerd. (dit proefschrift)

6. De tijd is rijp voor regionale dwarslaesiezorgketens, waarin alle revalidatieactiviteiten zijn geïntegreerd vanaf de acute opvang tot en met de follow-up na reïntegratie in de maatschappij. (dit proefschrift)

7. Bij het onderzoek naar de kwaliteit van behandelprogramma’s moet rekening worden gehouden met de “unmet needs” van de consument.

8. Om de eigen verantwoordelijkheid van de werknemer in het kader van de Wet Verbetering Poortwachter inhoud te geven, dient deze over een persoonsgebonden reïntegratiebudget te beschikken.

9. Een dwarslaesie is niet synoniem met doorsnijding van de banden met de samenleving.

10. De buitensporige prijs van medicinale cannabis in de apotheek zal de huidige discussie over het gedogen van coffeeshops doen veranderen in de promotie ervan.

11. Voor een optimaal evenwicht in belasting/belastbaarheid dient het schrijven van een proefschrift te worden ervaren als hobby en niet als werk.

12. In de opvoeding van adolescenten leveren ook ongevraagde adviezen een waardevolle bijdrage op weg naar volwassenheid.

13. Wie gelijk heeft hoeft niet te schreeuwen.

Marleen Schönherr, 17 december 2003